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STUDENTS WITH AUTISM SPECTRUM DISORDER SUPPORT WHILE ATTENDING A FOUR-YEAR INSTITUTION OF HIGHER EDUCATION

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STUDENTS WITH AUTISM SPECTRUM DISORDER SUPPORT WHILE
ATTENDING A FOUR-YEAR INSTITUTION OF HIGHER EDUCATION

by

Laurie J. Koehler Crawford

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Laurie J. Koehler Crawford

DEDICATION

This dissertation is dedicated to my family, Jeff, Christopher and Correy, who have been there through my academic journey with love, encouragement and an endless supply of hugs.

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My deepest appreciation and gratitude goes to my study participants. To Nathan, I am honored that you gave me your trust and shared your personal experience in an effort to help others who may pursue higher education and too, have ASD. To David and Richard, I hold sincere admiration for your dedication, passion and the understanding you both bring to supporting individuals with disabilities. To Sandy, I applaud your advocacy and desire to help Nathan move forward.

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Abstract

by Laurie J. Koehler Crawford

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2018

The number of children being diagnosed with Autism Spectrum Disorder (ASD), an impairment that affects an individual's social-communication abilities and behavior, is currently 1 in 68. An estimated 50,000 students who have ASD are reaching adulthood and exiting secondary education annually—a phenomenon known as the Autism Tsunami. There is a lack of services available to support this wave of young adults with ASD to be self-sustaining, contributing members of their communities. This is evidenced by the 37% of adults in their early 20s, who have ASD, and who have never worked or attended any postsecondary educational program. Due to the lack of appropriate accommodations in many of these programs, there is a low rate of completion for those who enroll. With an increase in positive educational outcomes in K-12 education, there are a burgeoning number of individuals holding the diagnosis of ASD able to enroll in postsecondary education at IHEs. For these students, the predicament of attending an IHE may pose unique challenges despite their ability to complete academic work. There

is an ever-increasing need to support individuals with ASD while they attend IHEs, however there is a scant amount of emerging literature on this topic.

This exploratory case study was conducted to gain an in-depth understanding of the ways in which Nathan, a student with ASD, was supported while he attended North Coast University (NCU), with the intent to inform further research, and affect the practice of service providers who work with students with ASD who are attending IHEs. The results of this study yielded an in-depth understanding of how NCU Disability Service providers, David and Richard, and Nathan's mother, Sandy, supported him as he attended NCU, and of his lived experience of support. The Interactional Model of Disability, a model that views disability as caused by both the individual's impairment and external environmental influences, was used as the theoretical lens in this study.

The findings of this study are as follows. Although Nathan has incredible perseverance and academic ability, without support he would not have had the same level of success. The early proactive, nonacademic approach to supporting students with ASD used by NCU was instrumental in Nathan's success and in helping him to become more independent. Coaching an intervention used as part of the NCU approach was highly effective for Nathan. David and Richard's dedication to positive student outcomes played a role in Nathan's success. Support from his mom was essential, but needed to be invisible. The ubiquitous nature of the issue of disclosure of disability emerged, as well as how Nathan experiences ASD.

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Chapter 1: Introduction

Introduction

The number of children being diagnosed with Autism Spectrum Disorder (ASD), an impairment that affects an individual's social-communication abilities and behavior, has increased tremendously over the past two decades in the United States, as well as globally (Elsabbagh et al., 2012). While once thought rare, the most recent estimates of children in the United States being diagnosed with ASD is now 1 in 68 (Center for Disease Control (CDC), 2015). The nosology of ASD having been the subject of extensive research in the late 20th century resulted in a broadening of the diagnostic criteria of ASD (American Psychiatric Association (APA), 1994; Fischbach, 2007). The new criteria, presented in 1994, allowed for more individuals with average and above average intelligence to be diagnosed with ASD (APA, 1994; Volkmar & Klin, 2009). As revealed through the research, and appropriately named, this disorder may present itself with a range, or spectrum, of symptoms and have a great deal of variance in how it affects an individual's ability to function in day-to-day life (APA, 2013). The ever-growing number of individuals identified as having ASD, greater understanding of the diversity among these individuals, and early intervention services, has presented an immediate need for expansion of support available to allow young adults with this impairment to be productive, contributing members of society (VanBergeijk, Klin, & Volkmar, 2008). The challenge faced is minimizing the disablement related to the

interplay between the intrinsic nature of the impairment in the individual and extrinsic societal factors. Included in this challenge is the need to identify and implement supports needed for individuals with ASD so they can attend, and be academically and socially successful at institutions of higher education (IHE) (Glennon, 2001; Smith, 2007; VanBergeijk, Klin & Volkmar; Wolf, Theirfeld, Brown & Bork, 2009).

ASD, or Early Infantile Autism as it was initially named, was first identified in the United States in 1943 by Dr. Leo Kanner (Fischbach, 2007; Smith 2007). ASD has evolved through several different diagnostic criteria and labeling. The most recent criteria were presented in the Diagnostic and Statistical Manual-5 (DSM 5) (APA, 2013). (DSM is the most common tool used to assign diagnoses of mental disorders in the United States). It is described therein as:

Autism Spectrum Disorder is characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships. In addition to the social communication deficits, the diagnosis of Autism Spectrum Disorder requires the presence of restricted, repetitive patterns of behavior, interests, or activities. (American Psychological Association, 2013, p. 31).

The approach to diagnosis in the DSM 5 provides for not only the presence of each of the two criteria, but also, the severity of the impairment (APA, 2013). This process of diagnosis intends to provide a greater understanding of the level of support the individual will need to engage in typical life activities for their age (APA, 2013).

With growing knowledge about the identifying features of ASD more children are being diagnosed and receiving interventions early, and, as needed, receive accommodations and interventions through primary and secondary education (VanBergeijk, Klin & Volkmar, 2008). As a result, many of these children are completing their secondary education with diplomas (Roux, Shattuck, Rast, & Anderson, 2015). These students are now able to consider postsecondary education at IHEs (VanBergeijk, Klin & Volkmar, 2008). Colleges and universities nationwide have reported a burgeoning number of students who have the diagnosis of ASD enrolling over the past decade (Barnhill, 2014; Roux, et al., 2015; Smith, 2007; Schlabach, 2008; VanBergeijk, Klin, & Volkmar, 2008; Wolf, Thierfeld Brown & Bork, 2009). In order to navigate the academic and social requirements of these IHEs, many of these students will need specialized and individualized support (VanBergeijk, Klin & Volkmar, 2008; Smith, 2007).

Students with ASD who experience the predicament of navigating a college campus may encounter challenges in academics, social interactions, and the ability to perform daily living activities (Adreon & Durocher, 2007; Cullen, 2015; Van Hees, Moyson & Roeyers, 2015; VanBergeijk, Klin, & Volkmar, 2008; Wolf, Thierfeld, Brown, & Bork, 2009). The degree to which ASD impacts an individual attending an IHE is highly variable, as is the type and amount of support needed to be successful (Gelbar, Smith & Reichow, 2014; Wolf, Thierfeld Brown & Borg, 2009). There is great variance from student to student and in the way each institution supports students with ASD (Huges, 2009).

The Americans with Disabilities Act (ADA) of 1990 and its amendment, the ADA Amendment Act 2008, mandates that IHEs must make “reasonable” accommodations for students with disabilities, ASD among them, when requested by the student. However, the law does not define “reasonable accommodations” (Brown, 2017; Smith, 2007; VanBergeijk, Klin & Volkmar, 2008). Each institution defines in what way they will accommodate students with ASD (Huges, 2009). There is no agreement as to how much support an IHE is required to provide to accommodate students with ASD (Glennon, 2001; Smith, 2007; VanBergeijk, Klin & Volkmar, 2008). Some argue accommodations should only be made in the area of academics since that is the chief mission of the IHE (VanBergeijk, Klin & Volkmar, 2008). At the other end of the continuum are those who advocate that all areas, including individualized social support, are reasonable accommodations as it is the institution’s responsibility to assist students in developing skills toward adulthood (Glennon, 2001; VanBergeijk, Klin and Volkmar, 2008). To that end there have also been a variety of models explored in a limited number of IHEs. Some of the accommodations are part of the provisions of the institution, while others are added and may cost families thousands of dollars (Barnhill, 2014; VanBergeijk, Klin & Volkmar, 2008). Many institutions are uncertain how to accommodate students with ASD (Smith, 2007). Often, institutions accommodate these students in the same way that they accommodate other students with very different disabilities (Smith, 2007; Wolf, Thierfeld Brown & Bork, 2009). This approach will likely not satisfy the needs of students with ASD. Smith (2007) states, “It is not the disability that must be accommodated but rather the individual needs of each student” (p. 516).

Families of students attending IHEs often provide a great deal of support to their child with ASD during the transition to, and attendance in IHEs (Barnhill, 2014). Many IHEs advocate for family involvement, particularly in the transition process, and attribute it to many students with ASD being able to complete their academic programs (Barnhill, 2014; Wolf, Thierfeld Brown & Bork, 2009). Often there is inadequate support from the IHE and the family fills the need (Wolf, Thierfeld, Brown & Bork, 2009). Limited research on family involvement indicate that it is welcomed by the students and can be attributed, solely or as a part of the students' ability to complete their IHE program (Crawford, 2010; Schlabach, 2008).

Despite an ever-increasing need to support individuals with ASD while they attend IHEs, there is only a small amount of emerging literature on this topic (Gelbar, Smith & Reichow, 2014) and much of it is antidotal (Van Hees, Moyson & Roeyers, 2015). Few studies have been conducted regarding support received and needed by individuals with ASD as they transition to and attend IHEs (Gelbar, Smith & Reichow, 2014; Roux, et al., 2015; Schlabach, 2008; Smith, 2007). Thus, postsecondary interventions remain sparse, and their effect has yet to be empirically confirmed (Gelbar, Smith & Reichow, 2014; Van Hees, Moyson & Roeyers, 2015).

Statement of Problem

The “autism tsunami” is upon us. Approximately 80% of the estimated 1.5 million individuals diagnosed with ASD in the United States are children (Advanced Futures for Adults with Autism, 2015). An estimated 50,000 students with ASD will reach adulthood each year and this is referred to as the “autism tsunami” (Sarris, 2014).

As with a true tsunami, if people are unprepared for it, the outcome can be devastating. The United States is not prepared to support the large numbers of individuals reaching adulthood who hold a diagnosis of ASD (Roux et al., 2015; Sarris, 2014). This is evident by the fact that 37% of individuals with autism, after exiting secondary education and in their early 20s, have never worked or attended any postsecondary educational program (Roux et al., 2015). The bleak outlook for this segment of our population is due to lack of support services available to assist them as they leave secondary education: leaving behind the mandated supports of special education (Roux et al., 2015). This unpreparedness results from a lack of research into the needs of these individuals as they transition into adulthood (Roux et al., 2015).

Autism research has been largely focused on the nosology, early diagnosis, cause, and early intervention areas of the disorder. The scant amount of research pertaining to needs of older individuals with ASD has been predominantly related to the more severe end of the spectrum. The impending crises and lack of services, has been recognized nationally as demonstrated by the signing of the Autism Collaboration, Accountability, Research, Education and Support Act of 2014 (CARES). The Autism CARES act recognizes the need for expansion in research and supports for adults with ASD (Roux et al., 2015). Increased research and services for students as they attend postsecondary education is among the needs cited in the act (Roux et al., 2015).

Current data available indicates the limited number of individuals with ASD who attend IHEs (2 year or 4 year), only a small number gain a degree (Jennifer Plumb, personal correspondence). A large number of these individuals do not have the needed support (Smith, 2007; VanBergeijk, Klin & Volkmar, 2008). Only 40% of those who

disclosed their disability of ASD to their postsecondary institutions reported receiving accommodations or some type of help (Roux et al., 2015). Failure to identify and provide support for capable individuals with a diagnosis of ASD in higher education will result in a large number of individuals who cannot support themselves (Roux et al., 2015). Wolf, Thierfeld Brown and Bork (2009) explain, without a college education, the job market is bleak since the largest expansion of jobs is in the service industry. Given the social nature of ASD, the service industry is not a viable option for many individuals with this impairment. They go on to explain, there is increasing numbers of individuals with ASD who will be under or unemployed. Individuals without jobs will pose a burden on their families, on insurance companies, and on federal and state social services. This is not only unnecessary; it is also critically unfair to a large group of people in our society (Volkmar & Klin, 2009).

There is an urgent need for research into support needed to allow students with ASD the opportunity to be academically and socially successful as they navigate IHEs (Van Hees, Moyson & Roeyers 2015). Development of evidence-based practices toward this success will pave the way toward employment, turning the tide on the current bleak outcomes for these individuals (Gelbar, Smith & Reichow, 2014; Van Hees, Moyson & Roeyers, 2015).

Purpose of Study

The purpose of this instrumental case study was to gain an in-depth understanding of the ways in which students with Autism Spectrum Disorder are supported while attending a four-year Institution of Higher Education, with the intent to inform further

research, and affect the practice of service providers who work with students with ASD while in attendance at institutions of higher education.

Research Questions

The overarching research question that has guided this study is: In what ways are students with Autism Spectrum Disorder supported while they attend a four-year institution of higher Education? In order to gain a comprehensive perspective of the support students with Autism Spectrum Disorder received while attending a four-year institution of higher education, the following sub-questions were explored.

1. In what ways are students with Autism Spectrum Disorder supported by the four-year institution of higher education that they are attending?
2. In what ways are students with Autism Spectrum Disorder supported by their families while attending a four-year Institution of Higher Education?
3. How do students with Autism Spectrum Disorder experience support while attending a four-year institution of higher education?

Significance of Study

Over the past 10 years, there have been repeated cries for research into all aspects of support for students with ASD while preparing for, transitioning to, and attending IHEs (Gelbar, Smith and Reichow's, 2014; Van Hees, Moyson & Roeyers 2015; Smith, 2007). The intended function of this in-depth case study was to improve and expand opportunities for individuals who meet the requirements to attend a four-year IHE, desire to attend a four-year IHE, and have ASD. To that end this study has contributed to the currently limited body of research in the area of support needs of individuals with ASD

while they are attending a four-year IHE. The in-depth understanding of the way a student with ASD is supported as he attends a four-year IHE provides insight upon which further research and provision of support may be based. With greater potential for appropriate support to complete an education in an IHE, more individuals with ASD will be able to play productive and meaningful roles in their communities, rather than being a financial burden, or incurring the devastation of the Autism Tsunami (Roux et al., 2015, Sarris, 2014; Volkmar & Klin, 2009).

Specifically this study provides information that can contribute to the development of evidenced-based best practices utilized by secondary educators, working with students transitioning to an IHE. While transition services are mandated by IDEA, as indicated in the National Autism Indicators Transition to Adulthood (2015), the outcomes for students once they exit from secondary education are very bleak. Thus, they are in need of remediation. Results of this study also provide insight for further studies that can refine and further identify evidence-based support practices of IHEs, and influence institutional attitudes toward the inclusion of students with ASD.

Definition of Terms

Autism Spectrum Disorder:

is characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships. In addition to the social communication deficits, the diagnosis of autism spectrum disorder requires

the presence of restricted, repetitive patterns of behavior, interests, or activities.

(APA, 2013, p. 31).

Authors note: this study was conducted post-DSM-5 release. To bridge the gap in diagnostic terminology from DSM–IV to DSM-5, the current diagnostic term, Autism Spectrum Disorder (ASD), will be used when presenting information found in earlier literature that used the diatonic labels “Asperger’s Syndrome” or “high functioning autism”. The exception will be a direct quote.

Disability: legal definition 1) As it refers to eligibility under the Americans with Disabilities Amendment Act of 2008:

(1) The term ”disability” means, with respect to an individual:

- (A) a physical or mental impairment that substantially limits one or more major life activities of an individual;
- (B) a record of such an impairment; or
- (C) being regarded as having such an impairment

(2) Experience of disability is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers (World Health Organization (WHO), 2015).

Impairment: is a problem in body function or structure (WHO, 2015).

Disability Service Office: A department on a college campus that exists to determine and ensure reasonable and appropriate accommodations and modifications for qualified students with documented disabilities, to assist students in self-advocacy, to educate the

community about disabilities, and to ensure compliance with the ADA, and Section 504 of the Rehabilitation Act (Valencia College, 2017).

Support or ASD-specific support: For the propose of this study, support refers to assistance that is needed, which is atypical of a neurotypical student, related to social/communication or behavioral patterns associated with a student having a diagnosis of ASD. Topics included are academics, independent living, and social, vocational and counseling needs in their article “Supporting More Able Students on the Autism Spectrum (VanBergeijk, Klin, & Volkmar, 2009).”

Summary

Worldwide there has been an increase in the number of individuals being diagnosed with Autism Spectrum Disorder (ASD) over the past two decades. Currently the CDC (2016) estimates that 1 in 68 children are being diagnosed with ASD in the United States. There is an estimated 1.5 million individuals in the United States diagnosed with ASD; 80% of these individuals are children. There is an anticipated 50,000 students with ASD exiting the secondary education system each year (Roux et al 2015; Sarris, 2014). This is referred to as the Autism Tsunami (Sarris, 2014). The United Sates is not prepared for the support needs of this population (Roux et al 2015; Sarris, 2014). Current postsecondary outcomes for this group is bleak, with 37% of individuals in their early 20’s having not attended any postsecondary education or having worked (Roux et al 2015). Included in the lack of preparation are many IHEs. There is a paucity of research on how best to accommodate and support students with ASD while attending IHEs (Gelbar, Smith & Reichow; Smith, 2007). For students with ASD to be

successful academically and socially while attending an IHE, accommodations and support that address their unique needs must be provided. Thus, there is an urgent need for increased research into the support needs of students with ASD that will lead to the opportunity for these students to be academically and socially successful as they navigate IHEs (Van Hees, Moyson & Roeyers 2015).

The remainder of this volume presents: a review of literature in Chapter Two, Research Methods in Chapter Three, Study findings in Chapter four, and Discussion of Findings, Conclusions, Implications for Practice and Recommendations will be presented in Chapter Five.

Chapter 2: Review of Literature

Introduction

This chapter presents a literature review that identifies intrinsic and extrinsic factors that relate to support needs and experience of students with the predicament of having Autism Spectrum Disorder (ASD), while attending a four-year institution of higher education (IHE). The first section of this chapter, “Disability: History, Models and Theory,” presents the phenomena of disability. ASD is among disabilities, included in laws that mandate equal access through accommodations. This section will provide insight into external factors; societal views and treatment of disability, legal provisions for accommodations, and theoretical lenses and models through which disability is viewed. Section two, Autism Spectrum Disorder: Clinical Definition, Prevalence and Predicament, delineates the intrinsic nature of this impairment through an in-depth discussion of ASD including; history, diagnostic criteria, prevalence changes, and insight into how ASD impacts day-to-day life of individuals attending four-year IHEs. The third and final section, Students with ASD attending IHEs: numbers, needs, IHE, and Family Support, presents what is known about the intersection of the intrinsic nature of ASD and the extrinsic factors at an IHE that need to be considered in supporting students with ASD at an IHE. Data regarding postsecondary outcomes, including attendance in IHEs is presented. This is followed by a discussion on unique needs for support and accommodations students with ASD may have, and what is known about support

provided by IHEs. The chapter concludes with the role of family in supporting students with ASD.

Disability: History, Models and Theory

The extrinsic factors that influence the experience of students with ASD, while attending a four-year IHE, stem from a society's concepts and treatment of individuals identified as disabled. ASD is included in the USA, as well as, in international documents as an impairment requiring societal accommodations. In order to understand the current sociopolitical treatment of disability, we must look at significant historic events and their impact on the contemporary models, theories, policies, societal beliefs and treatment of those with physical, sensory and psychological impairments.

History. As far back as one can find record of human societies, there is evidence of differential treatment of people with impairments (Barnes, 2010; Nunyi, 2012). A majority of the recorded societal treatment of this group of people was horrific (Davis, 2010 a; Nunyi, 2012; Smith, D., 2007). The view of the Greeks as reflected in Plato's writing was that "...deformed children be put away in some mysterious places" (cited in Nunyi, 2012). During the middle ages and the renaissance, it was common practice to leave deformed babies in the woods or throw them in a river (Smith, D., 2007). The early Christian doctrine viewed any impairment as a result of evil, God's displeasure, the impaired was an angel or beyond human status or disease and deformity was a means of purification (Munyi, 2012). There was no universal approach to disability, "either in the way disabled people are perceived or in the way societies responded to them" (Barnes p. 21). These attitudes changed in the late eighteenth and nineteenth centuries when

European cultures adopted the concept of the norm, which changed the way a society viewed human deviance. This resulted in the removal of the impaired from society and had a lasting impact on disabled people (Davis, 2010a; Munyi, 2012).

“The social process of disabling arrived with industrialization and with the set of practices and discourses that are linked to late eighteenth and nineteenth-century notions of nationality, race, gender, criminality, sexual orientation, and so on” (Davis, 2010a p.4). A scientific explanation for the status of the elite of the times and the concept of a norm was accepted in society (Barnes 2010; Davis 2010a). The term normal and the practice of normalizing entered European culture in the mid- nineteenth century when Quetelet transferred the concept of the “law of error”—used by astronomers in determining accuracy of their calculation of the location of stars—to the human condition (Davis, 2010a). Quetelet created *l’homme moyen* the average man, an abstract human made by averaging all human physical and moral attributes in a given country (Barns, 2010; Davis, 2010a). It implies that the majority of the population must or should somehow be part of the norm, particularly a normal body, and thus creating the concept of the disabled body— those outside of the norm (Davis, 2010a). Quetelet further adjusted the understanding of the normal curve using quartiles to rank order individuals, allowing the fourth quartile, though out of the norm to be considered superior for attributes such as intellect or height (Davis, 2010a).

Darwin’s Theory of Evolution published in 1859, described his observations of the processes of natural selection in the natural world, survival of the fittest, evolution is progress, and that progress is inherently beneficial (Davis, 2010a). When applied to humans, evolutionary ideas led to the rise of Social Darwinism a theory that distorted

legitimate scientific theory and applied it to society to implement extreme discriminatory practices against the impaired. In some areas, they were systematically removed from mainstream economic and social life (Davis, 2010a). During the Industrial Revolution, there was an industrial mentality that viewed workers as interchangeable and therefore sought to create a universal worker type whose physical characteristics would be uniform (Munyi, 2012). The ability to earn the means of subsistence independently was what society based one's social standing, merit, and personal identity on, thus impaired people who could not do the same work as the norm, were structurally devalued as socially inferior (Kimberlin, 2009).

From the general application of Social Darwinism emerged the next step in conceiving of the population as norm and non-norm. Galton presented his research on what he called "Eugenics". Based on the fears that deviant people were a threat to British and European society, the Eugenicists movement emerged with its intent to improve the race. Their aim was to do so by preventing the reproduction of those they viewed as defectives by means of sterilization and segregation (Barns, 2010; Davis, 2010a). The eugenicists tended to group all alleged "undesirable" traits together—the impaired, criminals, the poor and people of specific ethnicities (Davis, 2010a). The concept of eugenicists became widely accepted and practiced in Europe and the USA well into the twentieth century. It was this era in which "the medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit, and, significantly, as an individual burden and personal tragedy" (Liton, 2010 p. 224). The belief was that the individual was liable for their disadvantages and society sought to

occasionally mediate the effect of this disadvantage through charitable services or institutionalization (Baker, 2006).

World War II ushered in a shift in policy and treatment of disabled people as a result of the return of many injured veterans. There was a rapid increase in community-based services in both government and the private sector to help integrate veterans with impairments into the community, to normalize through cure, prosthesis, medical interventions, or rehabilitation (Davis, 2010a; Hiranandani, 2005). These shifts in policy and service transcended to the population at large. While the opportunity for participation in the community had increased, discrimination against the disabled had not disappeared but transformed (Davis, 2010a).

The 1960s marked the beginning of intensified efforts in North America, Scandinavia and Western Europe by disabled activists who sought a shift in attention away from the individual impairment as the sole cause of their dependency and marginalization (Medical Model) to a focus on "disabling barriers" (social, economic, cultural and political) as the cause of excluding disabled people from the mainstream society (Barnes & Mercer, 2010). These efforts are what Davis (2010b) describes as a first wave of any political/cultural movement against oppression. They involve the "establishment of the identity against the societal definitions that were formed largely by oppression. In this first phase, the identity—be it blackness, or gayness, or deafness—is hypostasized, normalized, turned positive against the negative descriptions used by the oppressive regime" (Davis, 2010b, p. 301). While all sought to emancipate the disabled, activist's approaches differed by country. Of these movements, the United States and

British movements have the greatest influence on the contemporary political and cultural climate for disabled students in higher education in the United States.

In the United States disabled activism emulated that of other minority groups seeking basic civil rights and equal opportunities. However, unlike other minority groups, disability—as a collective political and cultural movement—was new. It was the first time people with diverse impairments identified as a unified collective (Davis, 2010b). There was group solidarity for political ends, along with a unified agenda for the establishment of basic rights and prohibitions against various kinds of discrimination and ostracism (Davis, 2010b). These early efforts resulted in development of civil rights-based disability policies in the United States starting with section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 701 (1973), which states:

No otherwise qualified individual with a disability in the United States, as defined in section 705(20) of this title, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any executive agency or by the United States Postal Service.

The intent of this act was to eliminate discrimination based on disability in federally funded programs and services. Activists demanded expansion of their civil rights to include all services and opportunities, not just those that are federally funded. This occurred in 1990 with the passing of the Americans with Disabilities Act (ADA) (Pub. L. 101-336. 42 U.S.C., section 12102) which states:

It is the purpose of this chapter:

- (1) To provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities;
- (2) To provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities;
- (3) To ensure that the Federal Government plays a central role in enforcing the standards established in this chapter on behalf of individuals with disabilities; and
- (4) To invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities.

In the late 1990s and early 2000s, the Supreme Court and lower federal courts restrictive judicial interpretation of the term “disability” in cases relating to the ADA altered the intent of congress in its enactment of the ADA (Disability Rights Education & Defense Fund, 2017; Shaw, Keenan, Madaus & Banerjee. 2010). The Americans with Disabilities Amendment Act (ADAAA) was enacted to restore the broad scope of the definition of “disability” that Congress intended (Disability Rights Education & Defense Fund, 2017; Shaw et al., 2010). The ADAAA reaffirmed that Congress intended to include a wide range of physical disabilities, mental health disabilities, cognitive and learning disabilities, sensory disabilities, medical conditions and other impairment within the ADA’s nondiscrimination protections (S. 3406 (110th): ADA Amendments Act of 2008; (Shaw et al., 2010).

Section 504 of the rehabilitation act, the ADA and its 2008 amendment, ADAAA, are the protecting documents for the civil rights of disabled people in the United States. This includes equal access to educational opportunities at IHEs for “otherwise qualified”

individuals with documented disabilities. US. PL 94-142, Education for All Handicapped Children Act, put into law in 1975, which evolved into IDEA (the Individuals with Disabilities Education Act), upholds the civil rights of disabled students to have a free and appropriate public education in the least restrictive environment. This legislation applies to students in preschool through secondary education (IDEA). While this law does not apply to services for students in higher education, without the protections of this law, the opportunity for postsecondary education would not be possible for many disabled individuals since they would not have the prerequisite skills needed to enter college (VanBergeijk, Klim & Volkmar, 2008). Civil rights, or minority group, is the dominant platform in the US, however, removal of physical and social barriers was also a strong component of the movement. In the UK the focus was reversed, with the platform framed as social oppression-exclusion caused by social and physical barriers (Shakespeare, 2006). However, it also identified and demanded opportunity changes caused by discrimination (Shakespeare, 2006).

The Union for the Physically Impaired Against Segregation (UPIAS), formed in 1971, was the dominant influence in the disability rights movement in Britain and has had lasting influence worldwide (Shakespeare, 2006). This small, well-organized group (predominantly males with physical impairments) took a strong stance that disability was not a result of an individual's impairment, but rather a result of societal barriers resulting in exclusion (Shakespeare, 2006). The replacement of the deficit approach, medical model, with a social oppression view of disability was and remains very liberating for disabled individuals—it was not themselves, but society, which was at fault (Shakespeare, 2006, 2013). UPIAS has been celebrated as the inspiration for the British

disability movement, and concepts which Oliver later called the social model. This ideology became dominant within the British Council of Organizations of Disabled People (BCODP), founded in 1981, dominates the literature on contemporary social political writing about disability models and is found in decrees including the World Program of Action Concerning Disabled Persons adopted by the United Nations in 1982 (Shakespeare, 2006).

A disadvantage for a given individual, resulting from an impairment or disability that limits or prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors, for that individual" (As presented in Shakespeare, 2006 p. 88, United Nations, 1982).

Having accomplished to some extent the initial goal of any political/cultural movement against oppression the establishment of an identity—the disability movement began to evolve into the second wave (Davis, 2010b). This transition was fueled in the 1990s by the emergence of disability studies as a distinct field of study in the academic community (Barns & Mercer 2010). Having enjoyed the liberal models of disability established by the first wave, the second wave of the movement, being comfortable with their identity, moved on to self-examination (Davis 2010 b). In the second wave, the current state, the disability scholars and activists are looking to redefine the identity with greater nuance and complex ways, with differing opinions at times creating discourse with-in the movement (Davis, 2010b). There are a number of authors, and theorists seeking to expand on the very basic premise put forth by the social model of disability.

As scholars and activists refine definitions, theories, and create models relating to disability, contemporary society sees disability as a minority group. This was evident

when President Obama included disabled people in his acceptance speech in Grant Park. He stated: “It’s the answer spoken by young and old, rich and poor, Democrat and Republican, black, white, Latino, Asian, Native American, gay, straight, disabled and not disabled . . .”. Obama’s recognition of disability demonstrates the new attention and concern for disability as an essential category to be included the same as age, class, race, nationality, and sexual orientation (cited in Davis, 2010b).

Although rights policy has been expanded to include disability and thus, as a unified group have gained the status of a minority, the disabled continued to face discrimination and oppression. To advocate for their specific needs, subgroups such as the neurodiverse (ASD is among this group) have emerged. They are advocating for their place in society based on the accommodations needed to be included. Despite the legal mandates of 504 and ADA, disabled individuals are under-represented in higher education and in the work place (Silberma, 2013).

Models, theory and implications. In much of the disability literature it is the social model (social constructionist view) that is identified as the dominant approach to explaining the phenomena of disability. The Medical Model is often presented as a juxtaposed ideology to the Social Model. However, this black and white view is one of simplicity and does not take into account individual variables in the lives of the disabled (Wasserman, Asch, Blustein & Putnam, 2013). In recent years some disability scholars and activists have begun to examine these issues more closely as they seek theory and model that will better understand the lived experience of disabled people. The implications from these will be to better guide policy development, medical and social practices toward greater inclusion of disabled people in all aspects of society (Wasserman

et al. 2013). While there is a shift toward more holistic theories and models of disability, it is both the Medical and Social models that influence the daily lives of persons with impairments directly and indirectly through public policy, regulations, services and attitude.

The Medical Model views disability as a feature of the individual caused by disease, trauma or a health condition that must be remediated by medical treatment or intervention, to correct the problem of the individual. This essentialist view of disability, as noted above, began in the 1800s, as the concept of the norm was developed. It casts impairment as a deviance from the norm that is a pathological condition, as a deficit, and solely as an individual burden and personal tragedy (Davis, 2010b, Smith, C, 2007). Despite changes in attitudes, physical environment access and legal mandates that occurred in the late 1900s, the “medicalization of disability remains in practice and is deeply entrenched in the treatment of the disabled” (Linton, 2010, P.224). These practices have been referred as biopolitics, which indicate the various institutional, physical, administrative mechanisms, and knowledge structures, which enhance and maintain the exercise of power within the social body. It is these policies, extrinsic influences that disabled students must navigate to attend college and which each institution determines how they will implement (e.g., requirement of colleges for self-identification of having a disability to receive accommodations, types of services and attitudes) (Linton, 2010).

While scholars and activists renounce the medical model as a guide for policy development and social view of disability, there is recognition that the medical treatments that have increased the well-being of many disabled people, and ongoing attention by the

medical profession to the health and well-being of people with disabilities and to prevention of disease and impairments is critical (Linton, 2010).

The Social Model of disability defines disability entirely in terms of economic, environmental and cultural barriers. It shifted the view of disability from solely caused by biological deficits, to having nothing to do with individual bodies or brains (Shakespeare, 2006, 2014). In this model the environment is the target of intervention, rather than the individual with the impairment. That is society constructs disability and is responsible for its prevention through accommodations and removal of barriers to allow the disabled to participate as fully as possible (Shakespeare, 2006, 2014). A core concept in the Social Model of disability is the distinction of impairment, a deficit in organ or mechanism of the body, and disability, disadvantage or restriction imposed by limitations caused by physical or social barriers imposed by the society (Oliver, 2009; Shakespeare 2006; Kimberlin, 2009).

Despite the important role the Social Model has played, it falls short as a guide to policy and as the sole explanation of disability (Shakespeare & Watson, 2002). There are three factors that have emerged and should guide the development of theory, models, and practice (Shakespeare 2006, 2014). First, impairment cannot be disregarded. It is always present in the lives of the disabled. Craw asserts,

As individuals, most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence every aspect of our lives. We must find a way to integrate them into our whole experience and identity for the sake of our physical and emotional wellbeing, (as presented in Shakespeare 2014, p. 23).

Second, qualitative researchers such as Sherry and Thomas have found in their studies, using the Social Model, it is difficult to identify a clear distinction between impairment and disability (Shakespeare, 2006, 2014). Each study found that there was residual data that could not be attributed to impairment or social barriers (Shakespeare, 2006, 2014). Third, unlike other minority groups, removing oppression, discrimination or barriers, while helpful, does not eliminate the problematic nature of impairment. “Many impairments are limiting or difficult, not neutral...in most cases, disabled people are experiencing both the intrinsic limitation of impairment, and the externally imposed social discrimination.” (Shakespeare 2014, p. 29-30). The complex reality of impairment makes equalizing the situation for disabled people more complex and difficult than equalizing the situation for women and other minorities. Thus, the Social Model fails to adequately represent the lived experience of those with disabilities (Shakespeare, 2006, 2014).

As the study of disability evolves so do the models/theories that attempt to explain the phenomena. Emerging in the literature is a broadening of lenses being used to view disability including: Constructivism, all the Postmodernists, Structuralists, colonialist, Faulcolanians, critical theorists, critical realists and many others. The common thread of exploration with the different lenses has been to gain a greater understanding of the lived experience of disabled people through researching the effects of various social factors and the role they play in individual lives.

Critical disability theory has emerged as a dominant lens in disability studies research (Meekosha, & Shuttleworth, 2009; Barnes & Mercer, 2010). Critical disability theory is derived from the concept of Critical Theory of Society put forth by Max

Horkheimer in his essay “Traditional and Critical Theory” in 1937 (Bohman, 2013).

“Critical” theory may be distinguished from a “traditional” theory according to a specific practical purpose: a theory is critical to the extent that it seeks human emancipation, “to liberate human beings from the circumstances that enslave them” (Horkheimer, 1982, p. 244) (as presented in Bohman, 2013). Critical Theory is often thought of only as referring to the Horkheimer and others in the Frankfurt school. However, it also applies to any philosophical/research approach with the intended outcome “to critique society, raise awareness and change the balance of power of the less powerful” (Patton, 2002, p. 548) to connect theory with action. Critical disability theory offers a lens for unraveling the inherent complexities associated with disablement and equality with the assumption that theories of human rights and equality provide the necessary foundation for understanding the linkages between the existing legal, economic, political, and social rationales for the full inclusion of people with disabilities, and the systemic barriers and oppression that continue to construct people with disabilities as inherently unequal and disentitled to citizenship rights. (Rioux & Valintine, 2006). Critical Disability Studies provide valuable insight into topics as cultural representation and discourses to critical examination. However, “it is oriented more towards the academy than towards activism. It is hard to see practically how it could be operationalized” (Shakespeare, 2014 p. 71). It has produced little empirical study into daily-lived experience of individuals with impairments and their interaction with various attributes (Shakespeare, 2014).

To gain a greater understanding of the lived experience of disability it is imperative to move beyond the dichotomy of medical or social conceptualizations. Approaches that include; both impairments, societal factors and the role of their interplay

have been emerging: Nordic Relational Approach, Danermark and Gellersted; stratified or laminated system; Collier and the Interactional approach; Shakespeare (Shakespeare, 2006, 2014). The shift to inclusive conceptualization of disability stems from findings that impairment is ever present in the lives of the disabled and there are aspects of disability that make it difficult to determine the line at which impairment effects end and societal factors begin (Shakespeare, 2006, 2014).

Shakespeare's Interactional Model recognizes the multiple factors that need to be taken into account in understanding disability. The Interactional Approach conceptualizes disability as:

A complex and multifactorial phenomenon that results from the interplay of individual factors that relate to impairment and social factors. Disability is the outcome of the interaction between individual and contextual factors—which includes impairment, personality, individual attitudes, environment, policy, and culture. Rather than reserving the word disability for 'impairment effects' or 'oppression' or 'barriers' I would rather use the term broadly to describe the whole interplay of different factors, which make up the experience of people with impairments. Impairment is a necessary but not sufficient element in the disability relationship. It is always the combination of a certain set of physical or mental attributes, in a particular physical environment, within a specified social relationship, played out within a broader cultural and political context, which combines to create the experience of disability for any individual or group of individuals (Shakespeare 2006, p. 58).

The Interactional Model also accounts for the range and diversity of disability experience that may vary due to the nature and extent of the disability and individual attributes, personal attitudes and motivation (Shakespeare 2006, 2014). As Shakespeare explains, “It is not just the extent or nature of impairment, or the extent of the barriers and oppression that dictates the extent of limitation. For example, people with very similar impairments in the same society have different experiences, depending on their attitudes and reactions to their situation (2014, p. 82).

Predicament is a term Shakespeare uses to describe impairment (2006, 2014). He asserts that it captures the complexity of circumstances that surround the experience of impairment (Shakespeare 2006, 2014). He states, “Oxford Dictionary defines predicament as ‘an unpleasant, trying or dangerous situation’. Although still negative, this does not have the inescapable emphasis of ‘tragedy’. The notion of ‘trying’ perhaps captures the difficulties which many impairments present” (Shakespeare, 2014 p. 83). Thus, impairment understood as a difficulty, and as a challenge, and as something which we might want to minimize but which we cannot ultimately avoid (Shakespeare, 2014).

The underlying epistemological lens Shakespeare uses in his understanding of the social world and in his approach to his understanding of impairment and disability is critical realism (Shakespeare 2006, 2014). Critical Realists accept there is an external reality this is understood by the distinction made between ontology (what exists—being, things, reality objects of investigation) and epistemology (our ideas about what exists—knowledge, systems, thoughts, ideas, theories, language...) (Shakespeare, 2006, 2014). “That is there are objects independent of knowledge: labels describe, rather than constitute, disease. In other words, while different cultures have different views or

beliefs or attitudes to disability, impairment has always existed and has its own experiential reality” (Shakespeare 2014, p. 73).

The complexity and unique research by Shakespeare and others who bring a holistic view needed to gain an understanding of disability can be seen in its inability to be viewed the same as other groups identified as being oppressed. Hiranandani (2006) cautions the use of the Resiliency Model when regarding disabled people (2006). He explains the Resiliency model examines the inherent strengths of those who have overcome environmental, and social barriers despite oppression and discrimination. However, there are dangers in using this model with the disabled for it may give a false notion that anyone can overcome disability and accomplish amazing success-disabled heroes. What has been found is that most disabled heroes have exceptional social, economic, and physical resources that most people with disabilities do not have access to, thus resulting in better than average outcomes for them (Hiranandani, 2006). Under the Interactional Model, the interplay of resources in the disabled individual’s life and the intrinsic make-up of the individual determines the outcome.

Autism spectrum disorder: clinical definition, prevalence and predicament

Autism Spectrum Disorder has been used for many years to describe a group of complex brain disorders. In the May 2013 release of the Diagnostic and Statistical Manual (DSM 5), it became the single diagnostic label for these disorders. Despite recent progress in finding genetic links and environmental triggers that cause ASD, the biology of autism cannot yet be used diagnostically, and it must be defined by behavior (Lai, Lombardo, Chakrabarti, & Baron-Cohen, 2013). This section will present historic

benchmarks of the ASD diagnosis, prevalence rates and the range of impact ASD has on individuals with the impairment while attending four-year IHEs. ASD is an impairment included in the provisions of ADA, IDEA and other US and international mandates to accommodate.

From Kanner autism to a spectrum of disorders. Autism was first identified in the USA by Dr. Leo Kanner, a child psychiatrist, at John Hopkins University in Baltimore in 1943. He was the first to describe a distinct syndrome, "Early Infantile Autism", in his paper "Autistic Disturbances of Affective Contact". The term autism originated from Eugene Bleuler, who created the term to describe inward, self-absorbed aspects of schizophrenia in adults (Fischbach, 2007; Smith, C, 2007; *New England Journal of Medicine* as presented on "Autism Speaks". 2013; Wing, 1981). Kanner identified autism as a separate disorder. He observed that the children he saw had an early onset of symptoms, high intelligence, a profound preference for being alone and insistence on the preservation of sameness (Fischbach, 2007; Smith, C., 2007; *New England Journal of Medicine* as presented on "Autism Speaks", 2013). Not widely known in the US until 1991, when English translation was made available and earlier to a lesser degree through Lorna Wing's paper "Asperger Syndrome: a clinical account". In 1944, Hans Asperger, an Austrian physician, wrote about what he called "Autistic Psychopathy" (Wing, 1981; Wolf, Thierfeld Brown & Borg, 2009). His findings were in regard to a group of boys who appeared intellectually normal, however had limited ability in socializing, understanding nonverbal communication and had interest in a single topic or object (Smith, C., 2007). Wing titled the disorder as Asperger's Syndrome—psychopathy was misleading since it typically was equated with sociopathic behavior

(Wing, 1981). Wing, writes in reference to Kanner and Asperger's papers: "The two conditions are, in many ways, similar, and the argument still continues as to whether they are varieties of the same underlying abnormality or are separate entities" (1981).

Autism was first presented as a specific disorder in the second revision of *Diagnostics and Statistics Manual of Mental Disorders III (DSM III)* as "infantile autism". It was renamed as Autism Disorder 1987 in the revised addition of *DSM III* (*DSM III r* 1987). The *DSM* provides standard classification of mental disorders. It is the most common tool used to assign diagnoses of mental disorders in the United States (American Psychological Association, 2014). Disorders described in the *DSM* are identified by behavioral phenotypes, as there is no known biological means of identifying these disorders (Lai, Lombardo, Chakrabarti & Baron-Cohen, 2013; Ozonoff, 2013). It is periodically updated to increase reliability across clinicians and incorporated new research (Ozonoff, 2013). The *International Classification of Disorders 10 (ICD-10)*, currently is also used in identifying impairments, however not to the extent of *DSM* is in the US.

Following the appearance of Autism in the *DSM-III* there was increased research into this newly added disorder. These new findings were reflected in the subsequent version of *DSM IV*. *DSM IV*, released in 1994 (with update in 2000) that included autism under the umbrella category Pervasive Developmental Disorder (PDD). This umbrella included five disorders that all share impairment in reciprocal social interaction as the core diagnostic feature (*DSM IV* 1994, Volkmar et al., 2008). PDD included three autism disorders: Autism Disorder, Asperger's Syndrome and Pervasive Developmental Disorder Not Otherwise Specified (PDD, NOS), and two rare degenerative

disorders, Rett's disorder and childhood disintegrative disorder. PDD umbrella included individuals with a vast range of symptoms and degree of severity creating a spectrum of functioning (California Department of Developmental Services, 2007). At one end of the spectrum, referred to as high functioning, individuals are diagnosed as High Functioning Autism, Asperger's Syndrome, and PDD-NOS. At the other end, low functioning, diagnosis of Autism such as Classic Autism and Kanner Autism are found often with comorbidity of intellectual disability (California Department of Developmental Services, 2007). The PDD umbrella greatly expanded the high end of the autism spectrum by addition of the subtypes Asperger's syndrome and PDD, NOS. Individuals with these characteristics were not previously identified and make up a majority of those diagnosed under PDD. The *DSM IV* PDD diagnosis is based on identifying symptoms in three domains (often referred to as the triad of autism symptoms): social impairment, communication difficulties and repetitive/restrictive behaviors (APA, 1994; Wing, 1981).

The most recent revision of *DSM* was released in May 2013. Once again, there were significant changes regarding Autism. The *DSM 5* now only has one diagnosis, Autism Spectrum disorder (replaces PDD) (APA, 2013). There are no longer subtypes. The new diagnosis of ASD subsumes Autism disorder, Asperger's syndrome, Childhood disintegrative disorder and PDD, NOS. Rett Disorder was removed as it has been found to have a distinct identifiable biological origin, no longer requiring behavioral identification (Lia et al., 2013; Ozonoff, 2013). The *DSM-IV* presented three symptom sets or diagnostic criteria: social, communication, and repetitive, restrictive behavior. *DSM-5* has two: social communication and social interaction, and unusually restricted repetitive patterns of behavior, interests, or activities. Both of these criteria must be

present from early childhood and limit or impair every day functioning to be diagnosed as having ASD. The diagnostic criteria in the *DSM V* for these two criteria are as follows.

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative not exhaustive; see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures: to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers. (2013, p. 50).

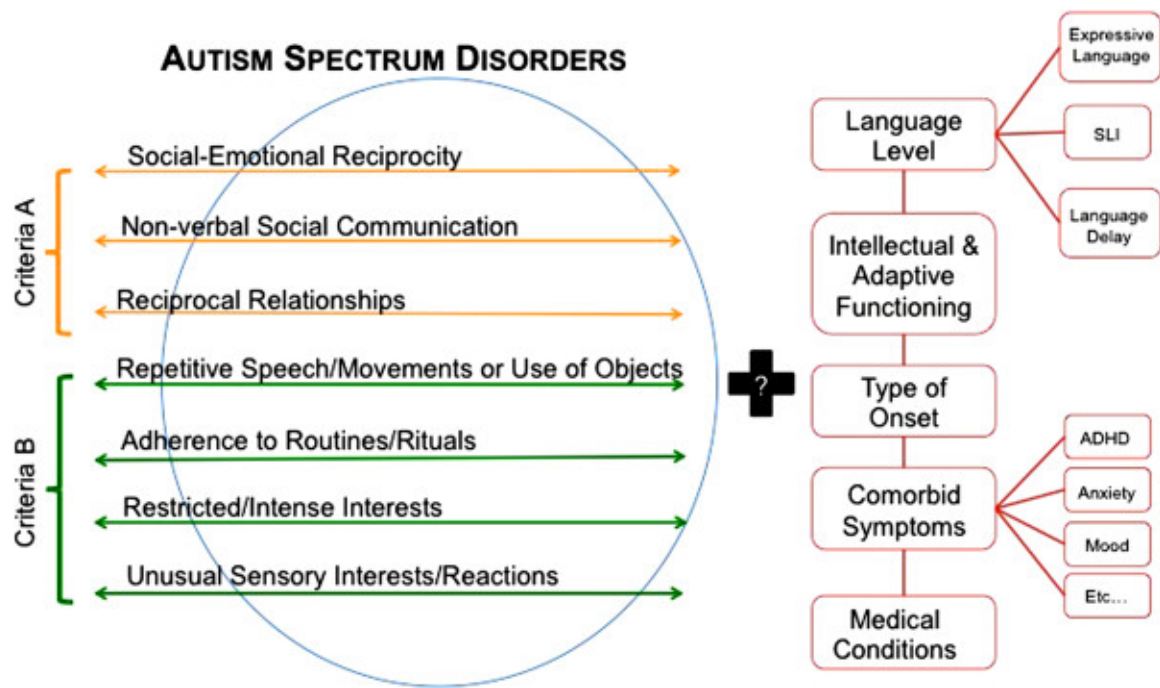
B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement). (2013, p. 50).

New to *DSM-5* is that each of the criteria sets must be given one of three ratings of severity (1. requiring support, 2. requiring substantial support, and 3. requiring very substantial support), thus, a spectrum of symptoms. The severity rating is based on support needed. In addition, current language and intellectual ability, onset age and pattern, and concurrent genetic/medical or environmental/acquired conditions are also recorded as separate factors (Grzazinski, Huerta & Lord, 2012; Lai, 2013; Ozonoff, 2013). In the article “*DSM-5* and Autism Spectrum Disorders (ASDs): an Opportunity for Identifying ASD Subtypes”, Grzadzinski, Huerta, and Lord present the below diagram that clearly depicts the *DSM-5* diagnosis specifications (Figure 1).

Figure 1. *DSM- 5* Diagnosis Specifications



The new *DSM-5* diagnostic criteria are in alignment with what is, thus far, known, or perhaps not known, about ASD, particularly the elimination of subtypes. There have been repeated studies and discussions as to where the boundaries of previously identified subtypes lie with findings leading to the unreliability in assigning diagnosis (Grzazinski, Huerta & Lord, 2012; Lai, 2013; Ozonoff, 2013). While the subtype diagnosis is not reliable, the diagnosis of ASD does seem to be consistent. Prior to the release of the *DSM-5*, studies were conducted to determine if those identified under Autism disorder, Asperger's Syndrome and PDD NOS criteria from *DSM-IV* would qualify under *DSM-5*. Findings indicate that there is close alignment (Grzazinski, Huerta & Lord, 2012; Lai, 2013; Ozonoff, 2013). To support the transition from subtypes to ASD, the following

instructive statement is found in the *DSM-5*. “Individuals with a well-established DSM-IV diagnosis of AD, Asperger, or PDDNOS should be given the diagnosis of ASD” (P. 51).

In addition to the clinical diagnosis, students (prior to college) may be determined to be eligible for Special Educations services under the category of autism if they meet the following criteria under IDEA 2004 (U.S. Department of Education, 2004).

- (i) Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three that adversely affects a child's educational performance. Other stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.
- (ii) Autism does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in paragraph (c)(4) of this section.
- (iii) A child who manifests the characteristics of autism after age three could be identified as having autism if the criteria in paragraph (c)(1)(i) of this section are satisfied.

An individual may have a medical diagnosis (using *DSM 5*) and not meet the educational criteria and vice versa; a student may meet the criteria under IDEA but not have a medical diagnosis. As noted above, SPED services under IDEA end upon exiting secondary education, however documentation of such services is one way of providing an IHE with verification of disability required to receive accommodations. A well-developed Individual Education Program (IEP) may serve as a blue print for the initial

accommodations and support services at the IHE (VanBergeijk & Volkmar, 2008). In addition to the IEP, as part of the transition to postsecondary life, IDEA also mandates that a Statement of Performance (SOP) be completed during the final year in secondary education (IDEA 1414(c)(5)(B)(ii)). While the SOP must contain a summary of academic achievement and functional performance, there is no specificity regarding the scope or depth of the information to be included in the SOP (IDEA 1414(c)(5)(B)(ii), 2004; Association for Higher Education and Disability, 2017; Shaw, Keenan, Madaus & Banerjee, 2010). As with a well-developed IEP, the SOP, if comprehensive, can serve as blueprint for an IHE in determining reasonable accommodations if the student qualifies under the Section 504 and ADA (AHEAD, 2017; Shaw et al., 2010).

Prevalence. It is estimated that there are 1.5 million individuals diagnosed with ASD in the United States, with 80% being children (“Advanced Futures for Adults with Autism”, 2015). It is estimated that 50,000 students with ASD will reach adulthood, each year and be exiting the public education system. This is referred to as the “autism tsunami” (Sarris, 2014).

The Center for Disease Control (CDC) estimates that 1 in 68 children (4.5 times as many boys) 1 in 42 as girls, 1 in 189 have been diagnosed with ASD based on data collected in 2012 at 11 CDC data collection sites (CDC, 2016). CDC data collection shows there was a continual increase in diagnosis of ASD since their data collection started in 2000, when the estimate was 1 in 150, until 2010 when the estimate was 1 in 68. The 2012 cycle of data collection indicated a leveling off, with the rate of diagnosis remaining steady at 1 in 68 (CDC, 2016). (See CDC Identified Prevalence of Autism Spectrum Disorder Chart 1 below.)

Table 1. Identified Prevalence of ASD

Identified Prevalence of Autism Spectrum Disorder ADDM Network 2000 – 2012 Combing Data from All Sites				
Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children...
2000	1992	6	6.7 (4.5 – 9.9)	1 in 150
2002	1994	14	6.6 (3.3 – 10.6)	1 in 150
2004	1996	8	8.0 (4.6 – 9.8)	1 in 125
2006	1998	11	9.0 (4.2 – 12.1)	1 in 110
2008	2000	14	11.3 (4.8 – 21.2)	1 in 88
2010	2002	11	14.7 (5.7 – 21.9)	1 in 68
2012	2004	11	14.6 (8.2 – 24.6)	1 in 68

Fombone (2012), who has been studying the prevalence of ASD for more than 20 years, asserts that the “broadening of the concept, the expansion of diagnostic criteria, the development of services, and improved awareness of the condition have played a major role in explaining this increase, although it cannot be ruled out that other factors might have also contributed to that trend” (Singer, 2012).

In addition to the continuing increase in prevalence, there has also been a shift in the characteristics of individuals being diagnosed with ASD. One such shift, which directly relates to the need for support in IHEs, is the increase in the percent of individuals who are diagnosed with ASD and have average to above average intellectual ability. Since the CDC has been measuring prevalence rates of ASD the rate of individuals with ASD who do not have the comorbid condition of Intellectual Disability

has steadily increased (CDC, 2015). Previously, the comorbidity of ASD and intellectual impairment was estimated to be 70% to 80% (California Department of Developmental Disability Services, 2007). Recent data from CDC (2015), indicates that 46 % of individuals diagnosed with ASD have average to above average IQ (CDC 2015).

Predicament of ASD in day-to-day lives at an IHE. The diagnostic criteria of ASD are presented above. However, this clinical description does not portray the predicament of navigating the day-to-day experiences of an IHE with ASD (Wolf, Thierfeld, Brown & Bork, 2009). What it does indicate is that this disorder is highly variable in nature, hence, spectrum disorder (APA, 2013). ASD is a very individualized disorder: no two people are affected in exactly the same way (Gelbar, Smith & Reichow, 2014; Wolf, Thierfeld Brown & Borg, 2009). Each individual manifests different patterns of strengths and challenges (Roux et al., 2015; Wolf, Thierfeld Brown & Bork, 2009). The diversity among individuals with ASD further increases when other individual intrinsic factors are considered, that include personality, life experience and comorbid conditions. It is these intrinsic factors of the student with ASD, in combination with extrinsic factors at the IHE, and societal influences that contribute to each student's day-to-day experience with ASD, or in Shakespeare's (2014) term, predicament. ASD is a lifelong neurodevelopmental disorder that is present throughout an individual's lifespan (APA, 2013). How ASD symptoms are manifested in an individual changes with age, experience and situation (APA, 2013; Wolf, Thierfeld Brown and Bork, 2009). The discussion below presents what is in the literature regarding how the features of ASD—social communication (ASD diagnostic criteria A), and behavioral patterns and

restrictions (ASD diagnostic criteria B)—along with other comorbid conditions, impact students with ASD while attending an IHE.

Based on the highly variable and heterogeneous nature of ASD, for some students there may be minimal effect on their ability to function in the college environment. In fact, some students thrive (Wolf, Thierfeld Brown, & Bork, 2009). That is, what made them different and unable to fit in socially or academically in high school, an intense focus and preoccupation on a single subject of interest is now what is expected and, in some cases, admired (Dillon, 2007; Wolf, Thierfeld Brown and Bork, 2009). However, for many students, ASD adds substantial challenges. For some it has a confounding effect on all aspects of their experience at an IHE (Adreon & Durocher, 2007; Austin & Valljo Pena, 2017) including academics, social relationships, and the ability to perform daily living activities (Adreon & Durocher, 2007; Cullen, 2015; Van Hees, Moyson & Roeyers, 2015; Wolf, Thierfeld Brown & Bork, 2009).

Academics: A student with ASD can encounter a variety of challenges academically that are different than their neurotypical peers (Adreon & Durocher, 2007; VanBergeijk, Klin & Volkmar, 2008). As with all aspects of ASD, academic performance is highly variable and individual.

Challenges may occur in academics due to the way language is processed by individuals with ASD (Wolf, Thierfeld Brown & Bork, 2009). That is, students with ASD “pay attention to the sequence of words rather than processing the meaning simultaneously. In other words, language is processed in the order in which it comes in, rather than reorganized and resynthesized. This may account for some of the over-literal features of AS” (Wolf, Thierfeld Brown & Bork, 2009, p. 21). Students with ASD often

lack flexibility in language comprehension, which presents difficulty in understanding sarcasm, figurative language and jokes (APA, 2013; Barnhill, 2014; Longtin, 2014; Wolf, Thierfeld Brown & Bork, 2009). They may have difficulty understanding the meaning of lecture material, particularly as more social contextual material or conversation occurs in the class (Wolf, Thierfeld Brown & Bork, 2009). Language difficulties may also make understanding assignments, tests and reading difficult (Wolf, Thierfeld Brown & Bork, 2009).

Social skills deficits associated with ASD also can have an impact on academic performance in class (Cullen, 2015). Students with ASD who have deficits in intuitive social knowledge, the lack of understanding and knowing how to engage in typical social behavior for the culture, may encounter difficulty in engaging in class activities (Barnhill, 2014; Dillon, 2007; Schlabach, 2008; Wolf, Thierfeld Brown & Bork, 2009). They may not know how to address the professor differently than their peers, they may dominate conversations in class, or have difficulty taking a role of a group member in completing group projects (Schlabach, 2008; Wolf Thierfeld Brown & Bork, 2009).

The behavior and sensory aspects of ASD, Criterion-B, can also pose challenges in an academic environment (Schlaback, 2008; VanBergeijk, Klin, & Volkmar, 2008); Wolf, Thierfeld Brown & Bork, 2009). Repetitive behaviors that individuals with ASD may engage in such as rocking, finger flicking, chewing on objects and many more, may appear to be purposeless behaviors or mannerisms (APA, 2013). However, these behaviors serve to reduce anxiety as well as to enhance focus for some students (Wolf, Thierfeld Brown & Bork, 2009). The challenge with some of these behaviors in a class setting is they may be distracting to others and/or drawn negative social attention to the student (Wolf, Thierfeld Brown & Bork,

2009). Some students with ASD may be hypersensitive to sound, lighting and smells (VanBergeijk, Klin, & Volkmar, 2008). They may respond to sensory experiences that the average person is not aware of and unable to easily filter out such as; sound of markers on a whiteboard, sounds or visual flickering of florescent lights, smells of hygiene products used by class mates or sounds of heating or air-conditioning (Wolf, Thierfeld Brown & Bork, 2009). These sensory experiences can be overwhelming and cause the student to lose focus or need to leave the environment. Students may have excessive adherence to routines and restricted patterns of behavior, which can result in distress even with small changes in routine or environment (APA, 2013; Wolf, Thierfeld Brown & Bork, 2009). For example, in the class environment, they may need to sit in the same seat and experience significant anxiety if the seat is taken (Wolf, Thierfeld Brown & Bork, 2009).

Although not a part of the diagnosis, a majority of students with ASD have Executive Function Disorder. This can affect a student's academic progress in that it affects a student's ability to manage time, plan, organize materials and thoughts, and maintain momentum in completing assignments (APA, 2013, Wolf, Thierfeld Brown & Bork, 2009).

In a class setting students with ASD often expend a tremendous amount of energy coping with the social communications demands of such an environment (Schlabach, 2008). To manage the energy demands of the class environment and the greater time needed for understanding what was presented in class, students with ASD often need to take fewer classes than the neurotypical student (Schlabach, 2008; Wolf, Thierfeld Brown & Bork, 2009). This prolongs the time it takes for degree completion.

Despite all these challenges, Van Hees, Moyson and Roeyers (2015) found students with ASD reported strengths associated with their unique way of taking in

information. They included: strong memory, focus precision and an eye for detail, dedication, the ability of putting one's mind to a subject, analytical skills, and remarkable powers of observation. Students with ASD have also reported that these skills contributed to their ability to excel in their specific disciplines (Schlabach, 2008; Van Hees, Moyson & Roeyers, 2015).

Social-student life. Social challenges have been discussed in regard to the completion of academic work, which is one facet of the social experience at and IHE. The social aspect of attending and residing at an IHE are vast and complex to navigate. For all students this is a time of great growth as they are responsible for themselves living away from families and home for the first time. However, this aspect of the college experience is far more challenging for students with ASD (Sarris, 2014). Having deficits in social/communication can make getting simple tasks done very difficult, and for some students without support impossible. Examples of this may be the need to know how to operate the laundry, how to report something is broken in a dorm room or learning where services are on campus (Wolf, Thierfeld Brown & Bork, 2009).

College is a time when there is a great deal of peer relationship building through shared experiences. Deficits in pragmatics, rules for using language within a social context, are characteristic of ASD (Adreon & Durocher, 2007; APA, 2013; Austin & Valljo Pena 2017, Wolf, Thierfeld Brown & Bork, 2009). Pragmatics involves verbal and nonverbal aspects of communication relating to both the input (comprehension) and output (production) of communication (Adreon & Durocher, 2007; APA, 2013; Wolf, Thierfeld Brown & Bork, 2009). These communication differences make the social aspect of the college experience very challenging for many students with ASD (Adreon & Durocher, 2007; APA, 2013; Wolf,

Thierfeld Brown & Bork, 2009). It may manifest as poor eye contact, unusual gestures, pedantic speech pattern, not engaging in social small talk, or difficulty understanding jokes, sarcasm, idioms and figures of speech (Adreon & Durocher, 2007; APA 2013; Wolf, Thierfeld Brown & Bork, 2009). Students with ASD may not know how to communicate reciprocally, including only talking about one's special interests and not inquiring about somebody else's interests (Adreon & Durocher, 2007; APA, 2013; Wolf, Thierfeld Brown & Bork, 2009). This lack of intuitive communication ability may make it appear that students with ASD are aloof or odd, not interested in social interaction or developing relationships; which is most often not the case (Adreon & Durocher, 2007; APA, 2013). Many students with ASD have a desire, often strong, to develop friendships, however their pattern of communication, lack of understanding of others verbal and non-verbal communication and difficulty with understanding the feelings of others, or social-emotional reciprocity, present challenges to developing relationships (Adreon & Durocher, 2007; APA, 2013; Dillon, 2007; VanBergeijk, Klin, & Volkmar, 2008).

In addition to difficulty in understanding and participating in conversation, students with ASD may also have difficulty with understanding nonverbal communication and they often do not understand the rules of behavior (informal and formal) (APA, 2013). These are rules we all seem to know without being told. We observe, we model, we learn, however, an individual with ASD must be explicitly taught (VanBergeijk, Klin, & Volkmar, 2008; Wolf, Thierfeld Brown & Bork, 2009). That is, they may not understand nonverbal body language or gestures indicating that a conversation is over, or it is time to leave (APA, 2013). Or, they may not have knowledge of unspoken rules of sharing space with a roommate (Wolf, Thierfeld Brown & Bork, 2009). Often students with ASD do not know that their behavior is

different from others. These difficulties with social/communication can result in alienation and students with ASD being isolated (APA, 2013; Schabach, 2008; Wolf, Thierfeld Brown & Bork, 2009). They may not know how to seek out friendships. These situations can impact the emotional well-being of a student (Wolf, Thierfeld Brown & Bork, 2009). Even those students who have learned the rules for social interactions, may experience emotional distress due to the effort and anxiety of consciously calculating what is socially intuitive for most individuals or struggle in novel unpredictable situations (APA, 2013). It can be emotionally taxing to engage in social situations (Adreon & Durocher, 2007; Walters, 2014). Lack of social knowledge can also result in students with ASD being taken advantage of, e.g., being left with a bill at a restaurant (Adreon & Durocher, 2007; VanBergeijk, Klin & Volkmar, 2004; Wolf, Thierfeld Brown & Bork, 2009). Students with ASD may also be taken advantage of sexually (VanBergeijk, Klin & Volkmar, 2004). They are often very naïve in the area of sexuality and do not know how to negotiate a simple dating situation or how to express feeling of interest in another individual, let alone, a more complex social situation involving a sexual relationship (VanBergeijk, Klin & Volkmar, 2004; Wolf Thierfeld Brown & Bork, 2009).

Activities of Daily Living, One of the most difficult and trying areas for any student, transitioning from high school to college and living away from home, is figuring out how to spend their time (Schlabach, 2008; Wolf, Thierfeld Brown & Bork, 2009). In most cases, students are going from a rigid 6 or more hours a day, highly-structured high school schedule to only having 12-15 hours per week of structured class time. The student is left to figure out how to structure the rest of his or her time. The student must identify what needs to be done and when. This includes scheduling time to study, eat,

sleep, do chores, socialize etc. Many students with ASD may experience profound deficits in their ability to manage this aspect of college life due to having executive function disorder and/or constraining routines (Dillon, 2007, Wolf, Thierfeld Brown & Bork, 2009).

Executive functioning “refers to a set of skills commonly associated with planning and foresight, organization, synthesizing information, delaying, and initiating activity” (Wolf, Thierfeld Brown & Bork, 2009, p. 91). While not every student with ASD has executive functioning, disorder, as many as 80% do (Wertz, 2012). As with other features of ASD, the extent to which an individual’s daily life is impacted by deficits in Executive Function is highly individual; it ranges from mild to profound and may relate to some activities of daily living but not all. As mentioned above, college students must schedule their time to include all daily/weekly activities. One area that the student with ASD may have difficulty with involves prioritizing and organizing activities. This becomes more challenging as new responsibilities are added on to an established routine (Wolf, Thierfeld Brown & Bork, 2009). These EF deficits may affect the broad level of organizing daily activities while simultaneously impact the student’s ability to carry out a single task such as, doing laundry, navigating food service or planning out and managing time for a complex academic task (Dillon, 2007; Wolf, Thierfeld Brown & Bork, 2009). A student’s ability to gauge the passage of time, or how much time is needed to complete work can also be a feature of Executive Function disorder. This can result in having many uncompleted assignments due to spending too much time on one assignment or not allowing enough time to complete work (Dillon, 2007).

A student with ASD may have a range of challenges with daily activities due to the need for structure and routines (Van Hees, Moyson & Roeyers, 2015). This relates to Criterion B of the ASD diagnosis—unusually restricted and repetitive patterns of behavior, interests, or activities (APA, 2013). Once a student establishes routines, if he or she is not able to carry them out, the student may not be able to progress to his or her next activity. For example, if he or she cannot get in the shower at an established routine time, they cannot move forward. Or, if there is construction and they cannot take their usual route to class, they may not go at all. Others may need to go to class very early to get the seat they prefer (Dillon, 2007). They may have the skills needed but cannot connect them as in the following case:

With a broken alarm clock, Zosia feared oversleeping for an 8:30 a.m. college class. Who wouldn't? But his solution was anything but typical; he decided to sleep in his classroom to make sure he wasn't late. As someone with Asperger's Syndrome, he lacked a so-called adaptive skill—in this case performing the steps needed to replace a clock battery—that makes adult life easier (Sarris, p. 201).

Another factor that may influence a student with ASD's ability to carry out needed daily activities, including their completion of academic responsibilities at the college is the presence of comorbid Psychiatric conditions (VanBergeijk, Klin, & Volkmar, 2008). Comorbid diagnosis is common in young adults with ASD: APA (2013) reports that about 70% of individuals with ASD have one comorbid mental disorder, and 40% may have two or more. The most common comorbid conditions include: Attention Deficit Hyper Activity Disorder, Anxiety, Depression and Turrets

Syndrome (APA, 2013; Adreon & Durocher, 2007; Brown, 2017; VanBergeijk, Klin, & Volkmar, 2008).

In order to explain how ASD may affect students while attending an IHE, this section examined the impact of ASD on separate domains that a student with ASD may experience, heightened challenges due to a given criterion of ASD and comorbid conditions. However, it is important to understand that students experience all of these simultaneously in their day-to-day lives, resulting in increased stress and mental health issues (VanBergeijk, Klin, & Volkmar, 2008; Van Hees, Moyson & Roeyers, 2015).

Students with ASD attending IHEs: data and support

An estimated 50,000 Americans who have the diagnosis of ASD are exiting secondary education each year, resulting in what is known as the Autism Tsunami. This is a time when young adults typically move forward, carving out their path toward adulthood and independence. However, for individuals who have ASD the terrain is often too treacherous to create a path. In the 2015 publication *National Autism Indicators Report Transition into Young Adulthood*, the outcomes for young adults diagnosed with ASD exiting the education system is bleak when compared to typically developing peers and peers with other impairments (Roux, et al., 2015). According to this report, 37% of individuals with autism were disconnected after exiting secondary education. These young adults who were in their early 20s had never worked or attended any postsecondary educational program (Roux, et al., 2015). Sixty-six percent of typically developing peers went on to attend college compared to 30% of those with ASD. Tsunami is used to describe this group because there are an overwhelming number of

individuals hitting the adult service system with a wide range of needs for services and supports, and our nation is unprepared for the wave. This includes supporting students with ASD who are capable of college level work. Despite at least a decade of calls for research on this topic, there is a paucity of empirical studies and data about numbers of students attending IHEs, how they are, or are not, supported and the outcomes (Roux et al., 2015; Barnhill 2014; Schlabach, 2008; Smith, 2007). This section will present what is known about support for students with ASD as they attend IHEs and will include: enrolment data available about this population, what is currently known about the support these students need and provisions of support by IHE and family.

Data. Despite currently being grossly under-represented in IHEs, in the past decade there have been reports of burgeoning numbers of students with ASD attending IHEs (Barnhill, 2014; Roux, et al., 2015; Smith 2007, Schlabach, 2008, VanBergeijk, Klin, and Volkmar, 2008; Wolf, Thierfeld Brown & Bork, 2009). There is little to no statistical data available relating to actual numbers of students with ASD enrolled at IHEs (Barnhill, 2014; Smith 2007; Schlabach, 2008; Wolf, Thierfeld Brown & Bork, 2009). One reason for the lack of available data is ASD has been included under psychological disorders by Disability Services Offices at IHEs. Each condition under that label is not independently recorded. A second factor is not all students choose to disclose their disability (Barnhill, 2014, Smith, C, 2007; Schlabach, 2008; Wolf, Thierfeld Brown & Bork, 2009). As IHEs are developing specific supports for students with ASD, they are beginning to collect separate data on enrolment and outcomes (Barnhill. 2014). The increase in students with ASD attending IHEs has been attributed to greater awareness of ASD which has resulted in more children diagnosed early with this disorder, and

receiving intervention before, and throughout their K-12 education (Ferrell, 2004; Gelbar, Smith & Reichow's, 2014; Schlabach, 2008; VanBergeijk, Klin & Volkmar, 2008). The number of students with ASD anticipated to seek this postsecondary path is expected to increase (Ferrell, 2004; Gelbar, Smith, 2007; Smith & Reichow's, 2014; Schlabach, 2008; VanBergeijk, Klin & Volkmar, 2008).

Student needs. There are enormous variables that must be taken into account when a student with ASD is heading to an IHE. It is where secondary education meets higher education, where intrinsic individual attributes meet extrinsic institutional and societal rules and expectations, and where independence and autonomy as an adult is to begin. These new experiences may be stressful for all students embarking on the journey from high school to college, however for students with ASD they are magnified (Adreon & Durocher, 2007; Auston & Vallajo Pena 2017; Glennon, 2001). As presented in the previous section, students who experience the predicament of navigating a college campus with ASD may encounter challenges academically, socially and in completing acts of daily life (VanBergeijk, Klin, & Volkmar, 2008; Wolf, Thierfeld Brown & Bork, 2009). There is variance in how ASD impacts each student's ability to successfully manage college life, as well as the amount of support they require (APA, 2013; Wolf, Brown & Bork, 2009). However, despite their abilities to complete the rigorous academic curriculum, many students with ASD will require supports in social, organizational, and communicative domains in addition to traditional academic accommodations to successfully meet the academic and social demands of the college environment (Adreon & Durocher, 2007; Dillon, 2007; Schlaback, 2008; VanBergeijk, Klin, & Volkmar, 2008, Wolf, Thierfeld Brown & Bork, 2009).

VanBergeijk, Klin and Volkmar (2008) discuss the need for individualized student support to occur even before the student arrives at an IHE. They present the concept of “goodness of fit” in regard to selection of an IHE. They assert that parents should assist the student in determining “the goodness of fit” in terms of the size of the university, typical class size and how amenable the IHE is to working with the students with varying disabilities, including ASD. Once an IHE is selected, students with ASD will need far more support in the transition process than their typically developing peers due to the social/communication and behavioral features of ASD (VanBergeijk, Klin & Volkmar, 2008). They will need to be explicitly taught many skills that others students have inherent social knowledge of and how to develop new routines (VanBergeijk, Klin & Volkmar, 2008; Wolf, Thierfeld Brown & Bork, 2009). While the IHEs express the importance of transitional support, many students do not receive any, others have supports built into their secondary education and for others the IHEs provide transition support (Barnhill, 2014; VanBergeijk, Klin & Volkmar, 2008).

IHE Support. Each IHE has its own approach to providing support to students with disabilities; ASD among them. However, in doing so they all must meet legal mandates to accommodate.

Mandate to accommodate. As presented earlier in this chapter, Section 504 of the rehabilitation act, the ADA and its 2008 amendment, ADAAA, are the legal mandates in the US that provide protection against discrimination based on disability. The Americans with Disabilities Act (ADA) (Pub. L. 101-336. 42 U.S.C., section 12102) and its 2008 amendment, (ADAAA) (S. 3406 (110th): ADA Amendments Act of 2008, mandate; IHEs provide “reasonable accommodations” for students with disabilities, who are

otherwise, qualified. The accommodations must be made to ensure students with disabilities have equal access to education provided, without altering the essential elements of the academic programs (Dillon, 2007). ADA does not define “reasonable accommodations” (Brown, 2017; Smith 2007; VanBergeijk, Klin & Volkmar, 2008). There is great diversity in what are considered “reasonable accommodations” for students with ASD at an IHE (Barnhill, 2014; Huges, 2009; Smith, C., 2007). Some institutions interpret ADA as needing to only provide accommodations in the area of academics, since that is the chief mission of the IHE (Glennon, 2001; Smith 2007; VanBergeijk, Klin & Volkmar, 2008). Some advocates assert that “reasonable accommodations” should apply to all aspects of the college experience (Glennon, 2001; VanBergeijk, Klin & Volkmar, 2008). Glennon (2001) explains:

The mission of any college or university, however, is not simply academic advancement. The overall goals of any university experience include developing skills for adulthood, forming life-long relationships, identifying a vocational pathway, and/or participating in extracurricular activities. If ADA states that individuals with a disability cannot be excluded from participation in services, activities, or programs of a public entity, then all of these activities would need to be supported (p. 185).

Thus, each institution defines in what way they will accommodate students with ASD. (Glennon, 2001; Huges, 2009, Smith 2007; VanBergeijk, Klin & Volkmar, 2008).

In order for college students with ASD to receive accommodations they must self-disclose and present documentation of their disability (Adreon & Durocher, 2007; Barnhill, 2014; Dillon, 2007; Longtin, 2014; Schlaback, 2008; VanBergeijk, Klin, &

Volkmar, 2008; Wolf, Thierfeld Brown & Bork, 2009). Typically IHEs have a Disabilities Services Office that is responsible for arranging for accommodations (Longtin, 2014). It is there that students must request accommodations and support.

For students who have received special education services, under IDEA, in the K-12 education system, this is a shift from having needs identified and services provided, for the most part without request, to having to request all accommodations and support; or a shift from a framework of entitlement, IDEA, to a framework of equal access and protection from discrimination, ADA/ADAAA, (Van Bergeijk, Klin, & Volkmar, 2008). Many students with ASD do not request services (Wolf, Thierfeld Brown & Bork, 2009). There are three primary reasons for students not requesting services. Two of these relate to the deficit features of ASD—not having the knowledge of how to ascertain accommodations at an IHE and the lack of communication/self-advocacy skills to do so (Crawford, 2010; Wolf, Thierfeld Brown & Bork, 2009). A third reason, students choose not to disclose is to avoid the stigma associated with disability (Barnhill, 2014; Hammond, 2014; Wolf, Thierfeld-Brown & Bork, 2009).

IHEs provision of accommodations and supports for students with ASD.

Since the early 2000s there have been increased numbers of students with ASD attending IHEs and requesting accommodations. A study, conducted by Smith (2007), concluded that students with ASD were accommodated in the same way as students with other disabilities. Smith asserts that this will not satisfy the needs of this population, and that with this unique disorder comes the need for unique accommodations to be made on an individual basis. Smith states, “It is not the disability that must be accommodated but rather the individual needs of each student” (p. 524). Smith, along with other early

authors on the topic of students with ASD attending IHEs, expressed the need for research to discover what types of accommodations and support is needed for these students to be academically and socially successful (Glennon, 2001; Dillon, 2007; VanBergeijk, Klin, & Volkmar, 2008). Yet, with the passing of 10 years, there remains a dearth of scholarly studies on this topic. This is evident by the results of Gelbar, Smith and Reichow's (2014) systematic review of peer-reviewed literature pertaining to supporting individuals with ASD while attending IHEs. Their review yielded 20 articles. They describe the literature as containing "fragmented descriptions of programs, experiences, and theoretical suggestions for effective programs" (p. 2599). Since this review in 2014, a small number of studies on issues and support related to students with ASD attending IHEs has emerged, among them Barnhill's (2014) and Brown's (2017) studies. Both studies inquired about the types of accommodations and supports provided at IHEs for students with ASD. Barnhill's data was collected from IHEs that offered "structured programs" for students with ASD. Brown's (2017) study gathered data from a nationally representative and randomly selected sample of postsecondary institutions. The data from these studies will be discussed below as it relates to the body of literature on accommodations and supports provided by IHEs to students with ASD. Research is still in its exploratory stages. IHE disability professionals based their support largely on anecdotal accounts and recommendations by other professionals (Morrison, Sansosti & Hadley, 2009).

Support provided by the IHE directly to students with ASD at IHEs can be grouped into three categories: academic accommodations, general support and ASD specific support (Brown, 2017). However, these categories do not have clear boundaries

due to the diversity in the approach IHEs take in providing services to students with ASD, and due to lack of consistency in terminology in the literature. In addition to direct support to students with ASD, IHEs may provide indirect support through educating the campus community, including faculty, on the predicament of ASD at a college campus and how they may best support these students (Barnhill, 2014; Wolf Thierfeld Brown & Bork, 2009). To assist in their provision of support at the IHE, some IHE Disability Support Professionals interact with family members of the students (Barnhill, 2014; Crawford, 2010; Wolf Thierfeld Brown & Bork, 2009).

Academic accommodations. Academic accommodations are governed by provisions of the ADA known as “reasonable accommodations” which refers to the “change in the work or school environment or in the way things are customarily done that enables an individual with a disability to enjoy equal opportunities” (42 U.S.C. sec 121001). Both Barnhill (2014) and Brown (2017) found that IHEs provide accommodations with an academic focus more frequently than accommodations and other supports with a sensory or social/communication focus. This is in alignment with prior literature (Dillon, 2007; Smith, C, 2007; VanBergeijk, Klin, & Volkmar, 2008; Wolf, Thierfeld-Brown & Bork, 2009). Yet, It is the social/communication and behavioral/sensory features of ASD that often impede functioning at an IHE for students with ASD (Adreon & Durocher, 2007; Barnhill, 2014; Brown, 2017; Dillon, 2007; Smith, 2007; VanBergeijk, Klin, & Volkmar, 2008; Wolf, Thierfeld Brown & Bork, 2009). That is not to say that academic accommodations are not important to students with ASD. As discussed above in the Predicament of ASD and Student Needs sections of this chapter, students with ASD may need academic accommodations due to the

social/communication-diagnostic criterion A, restrictive/repetitive behaviors-diagnostic criteria B, and/or comorbid conditions including executive function disorder, ADHD, anxiety, depression (APA, 2013; VanBergeijk, Klin, & Volkmar, 2008; Wolf, Thierfeld Brown & Bork, 2009). It is not simply the provision of an accommodation that makes it beneficial “for accommodations to be effective, they must fit the students’ functional limitations (Brown 2014, p. 144)”. Thus, for the accommodations to be beneficial they must address a functional limitation of the student (Brown, 2017).

Types of academic accommodations, identified in both Barnhill’s (2014) and Brown’s (2017) studies, being provided for students with ASD include: use of extra time on tests, alternative testing location, receiving copies of lecture notes (from note taker, professor or peer), priority registration, and use of technology supports, including audio recording lectures. These academic accommodations are not unique to students with ASD. These findings are congruent with prior literature on academic accommodations (Crawford, 2010; Wolf, Thierfeld Brown & Bork, 2009).

General supports services. Students with ASD may also get needed support relating to the challenges associated with their ASD through IHE general support services (Brown, 2017). These services “provide transition, educational, and social support beyond the level of reasonable accommodations; however, they are programs offered by institutions to a variety of students (Brown, p. 145).” They may include programs such as summer transition to college programs, academic supports such as tutoring, peer mentoring, career counseling and counseling services (Brown, 2017; Barnhill, 2014). At some IHEs these same types of supports services are offered under ASD-specific services (Barnhill, 2014).

ASD-specific support (services). “ASD-specific service refers to any service specifically designed to support students by targeting the functional limitations associated with ASD (Brown, 2017, p .145)”. Brown (2017) found 30.5 % of respondents (n=466) offered ASD-specific support services, 28.3% provided the services free of charge, and 2.2% for an additional fee. Barnhill’s (2014) study of IHEs that offered ASD-specific support (n=30) found 36.6% of the IHEs did not charge for the ASD specific support services. The remaining IHEs, 66.3%, charged additional fees for the ASD-specific services that ranged from \$1,050.00 to \$17,400.00 above the standard tuition and room and board, with the average being \$6,525.00. This data represents an increase in ASD-specific support since Smith’s study (2007). Barnhill’s (2014) research revealed that the professionals working with this population were very committed to the success of students with ASDs. Professionals also reported that working with this population was very time intensive (Barnhill, 2014; Schlabach, 2008).

Literature on ASD-specific supports at IHEs present a wide variance on what specific services are provided, to what degree, and by whom (Barnhill, 2014; Brown, 2017; Gelbar, Smith & Reichow, 2014; Schlabach, 2008). Most frequently mentioned in the literature are services involving support with living arrangements (most often noted, a single room), mentoring programs, support groups, transition and support related to executive functioning (Barnhill, 2014; Brown, 2017; Gelbar, Smith & Reichow, 2014; Longtin, 2014; Schlabach, 2008).

As part of the transition to an IHE, and to a lesser extent thereafter communication with families of students with ASD has been reported by some IHE Disability Service Professionals as an important and valuable piece of the process of

supporting students (Barnhill, 2014; Crawford, 2010; Dallas, Ramisch & McGowan, 2015; Schlabach, 2008; Shmulsky, Gobbo & Donahue; Wolf, Thierfeld Brown & Bork, 2009). Wolf, Thierfeld Brown and Borg (2009) contend that family involvement with the ASD population is imperative due to the communication deficits among this population. Involving family members can help expedite the process of identifying student needs for accommodations and support, for the Disability Service Personnel, while actively involving the student, and making the family feel supported. The authors urge that the partnership should begin before each student arrives on campus to allow information to be gathered by the Disability Services Professional, about prior support and accommodations, and to what extent transition services have prepared the student for the move to the IHE. There is great variance in the approach IHEs employ in involving families. Some IHEs engage each family individually while others, have a transition program that gathers student profile information on an individual basis and provides a group information session for parents (Shmulsky, Gobbo & Donahue, 2015). It is important to note that IHEs that foster partnerships with families can only do so with the student's permission due to the Federal Educational Records Privacy Act (FERPA) (Shmulsky, Gobbo & Donahue, 2015; Wolf, Thierfeld Brown & Borg, 2009).

IHE next steps in supporting students with ASD. With only a scant amount of research, and a burgeoning population of individuals with ASD heading for IHEs there is an immediate need for further research as to how best to support these students as they prepare for, and attend IHEs (Gelbar, Smith & Reichow, 2014; Morrison, Sansosti & Hadley, 2009; Shmulsky, Gobbo & Donahue, 2015). Research on this topic is still largely in its exploratory phase; there is a lack of evidence-based practices for supporting

students with ASD (Dallas, Ramisch & McGowan, 2015; Gelbar, Smith & Reichow, 2014; Shmulsky, Gobbo & Donahue, 2015).

There is a call for research that will provide a more detailed picture of the strategies for support and accommodations that promote positive experiences for individuals with ASD attending IHEs (Dallas, Ramisch & McGowan, 2015; Morrison, Sansosti & Hadley, 2009). In order to gain a comprehensive view of supports and services, data should be gathered from all stakeholders involved in supporting students with ASD while they are attending an IHE (student, family, DSP professionals and other agencies involved) (Dallas, Ramisch & McGowan, 2015). Emphasis must be placed on the importance of exploring the perceptions of college students with ASD regarding the supports and accommodations they find to be most useful (Dallas, Ramisch & McGowan, 2015; Morrison, Sansosti & Hadley, 2009). This is in keeping with the concept of “Nothing About Us, Without Us”—a slogan that was employed by disability activists that asserts the belief that individuals with disabilities should be directly involved with issues pertaining to them (Dallas, Ramisch & McGowan, 2015). This data should be from a variety of colleges and universities, and include longitudinal studies (Dallas, Ramisch & McGowan, 2015; Shmulsky, Gobbo & Donahue, 2015). Data to be examined should also include student retention and graduation rates, in relation to the support received, and postgraduate outcomes of students who successfully complete their degree programs (Barnhill, 2014; Shmulsky, Gobbo & Donahue, 2015).

The intent of future research must be two-fold. First, as presented above to provide IHE professionals with best practices for supporting students with ASD through the development of evidence-based practices and models (Barnhill, 2014; Gelbar, Smith

& Reichow, 2014). Second, it must inform the practice of the K-12 education system (Gelbar, Smith & Reichow, 2014). This is a critical aspect of this research given that “Currently, the K-12 system assumes, given the academic achievement of higher-functioning individuals with ASD, that they will be successful in postsecondary environments” (Gelbar, Smith & Reichow, 2014, p. 2599). Data on postsecondary outcomes of individuals with ASD contradict this assumption (Gelbar, Smith & Reichow, 2014; Roux, et al, 2015). In addition to being under represented at IHEs, data indicate that adolescents and young adults with ASD often experience depression, anxiety, and loneliness (Gelbar, Smith & Reichow 2014). Thus, research should provide K-12 educators with information on what preparation has been effective toward preparing students with ASD for attending an IHE, and what still needs to be developed (Gelbar, Smith & Reichow, 2014).

Role of Family in Supporting Students with ASD as They Attend IHEs. As with other aspects of support for students with ASD as they attend a four-year IHE, there is a dearth of data on the role of family in supporting their family member with ASD, as he/she attends an IHE (Dallas, Ramisch & McGowan, 2015). The literature does not hold any studies, or studies in part, that have specific inquiry into the role of family supporting students with ASD as they attend an IHE (Dallas, Ramisch & McGowan, 2015). However, family/parent support has emerged as themes in a number of qualitative studies that inquired about topics relating to students with ASD planning for or in attendance at IHEs (Dallas, Ramisch and McGowan, 2015). What has consistently emerged in the themes is: parents are most often the family members providing the support and parental support is reported to be valued, often reported as what made it

possible for students to succeed, and wanted by the students and IHEs (Barnhill, 2014; Crawford, 2010; Mitchell & Beresford, 2014; Schlabach, 2008; Shmulsky, Gobbo & Donahue, 2015). The support provided by parents is reported to be in nonacademic areas (Barnhill, 2014; Crawford, 2010; Mitchell & Beresford, 2014; Schlabach, 2008; Shmulsky, Gobbo & Donahue, 2015). There are several areas of parental support that appeared repeatedly. They include: coordinator/advocate, emotional supporter, social interpreter, and daily living activities supporter (Barnhill, 2014; Mitchell & Beresford, 2014; Schlabach, 2008; Shmulsky, Gobbo & Donahue, 2015).

The coordinating/advocate role is most predominant during the planning for and initial attendance at IHEs (Barnhill, 2014; Mitchell & Beresford, 2014; Schlabach, 2008; Shmulsky, Gobbo & Donahue, 2015; Szentmiklosi, 2009). This role includes assisting in identifying IHEs to visit, setting up the visit, communicating on behalf of the student in soliciting services from IHE disability services programs, and, as discussed above, communicating with the disability services personnel about the student's needs (Barnhill, 2014; Mitchell & Beresford 2014; Schlabach, 2008; Shmulsky, Gobbo & Donahue; Szentmiklosi, 2009; Wolf, Thierfeld Brown & Bork, 2009). This role often lessens as the student becomes more accustomed to their new environment (Barnhill, 2014; Shmulsky, Gobbo & Donahue, 2015). Mitchell and Beresford (2014) report, based on student response, that during the transition phase, parents often re-provided information gathered regarding the transition in a simpler manner and at a time when they were able to process the information. That is, the transition process was often overwhelming to the student and parents know how and when to reintroduce the information.

Emotional supporter and helping daily living activities were reported to be ongoing roles the parents had throughout the child's attendance at an IHE (Michell & Beresford 2014; Schlabach, 2008; Shmulsky, Gobbo & Donahue; Szentmiklosi; 2009; Wolf, Thierfeld Brown & Bork, 2009). Students reported that they valued their parents' emotional support because it was "on-tap"; the support was available when needed and their parents understood their individual needs, and how autism impacted their life (Michell & Beresford, 2014). Ongoing support with daily living activities may include helping with chores, laundry, most frequently noted, and scheduling doctor appointments.

Dallas, Ramisch, and McGowan (2015) warn that while family involvement is reported as positive to student success, there is no data to support this belief. The authors state it is unclear whether or not family members should be involved in postsecondary educational settings, what potential roles would be, or if family member involvement would be beneficial for students with ASD (p.142). They go on to recommend that research be conducted regarding the role of parents in relation to positive outcomes for students attending IHEs.

Summary

This chapter presented a literature review that identifies intrinsic and extrinsic factors that relate to support needs and experience, of students with the predicament of Autism Spectrum Disorder (ASD), while attending a four-year institution of higher education (IHE). The extrinsic factors are presented in the first section. History of disability is presented including the legal mandates for accommodation and models and theory of the phenomena of disability. Section two, discussed the intrinsic nature of

ASD. This included clinical definition, in-depth discussion of this impairment from a clinical standpoint including prevalence data. It also examines the predicament of ASD as it relates to a student at an IHE. The final section discusses the issues relating to support for students with ASD while attending an IHE.

Chapter 3: Methodology

Introduction

The purpose of this case study was to gain an in-depth understanding of the ways in which a student with Autism Spectrum Disorder (ASD) is supported while attending a four-year Institution of Higher Education (IHE), with the intent to inform further research, and effect the practice of service providers who work with students with ASD during transition to, and while attending IHEs. As described in Chapter 2, Literature Review, there is a dearth of information on the topic of support for students with ASD attending IHEs. This study was exploratory in nature since it sought to gain information about a topic for which there is little known data (Patton, 2002).

Qualitative methodology was used in this study. Qualitative methodology is concerned with “understanding the meaning people have constructed, that is, how people make sense of their world and the experiences they have in the world” (Merriam, 2009, p. 12). In this methodology the researcher is the primary instrument of data collection and analysis, inductive investigation strategies are used, and the end product of the study is a thick rich description (Merriam, 2009; Patton, 2002). Qualitative findings are derived primarily from in-depth open-ended interviews, direct observation and written documents (Patton 2002).

The selection of a qualitative methodology was twofold. First, as Patton (2002) asserts, “when little is known about the nature of a phenomenon, qualitative inquiry is a reasonable beginning point for research” (p.193). Second, the function of a qualitative

inquiry is to gain a deep understanding of a phenomenon “from the standpoint of those who lived it” (Merriam & Associates, 2002, p. 142). Thus, qualitative methodology provided the means to gain in-depth information about the phenomenon of support experienced by a student with ASD as he attended a four-year IHE in a real-life context.

The following questions guided this study’s design, data collection, and analysis. The overarching research question that has guided this study is: In what ways is a student with Autism Spectrum Disorder supported while he attends a four-year institution of higher Education? In order to gain a comprehensive perspective of the support the student with Autism Spectrum Disorder received while attending a four-year institution of higher education the following sub-questions were explored.

1. In what ways is a student with Autism Spectrum Disorder supported by the four-year institution of higher education he is attending?
2. In what ways is a student with Autism Spectrum Disorder supported by his family while attending a four-year Institution of Higher Education?
3. How does a student with Autism Spectrum Disorder experience support while attending a four-year Institution of Higher Education.

This chapter will present the design of the study. This section will include a description of the case and methodology used in case selection. This will be followed by a description of data collection, data analysis, theoretical lenses used in the study, researcher bias, credibility and consistency practices employed study assumptions and limitations.

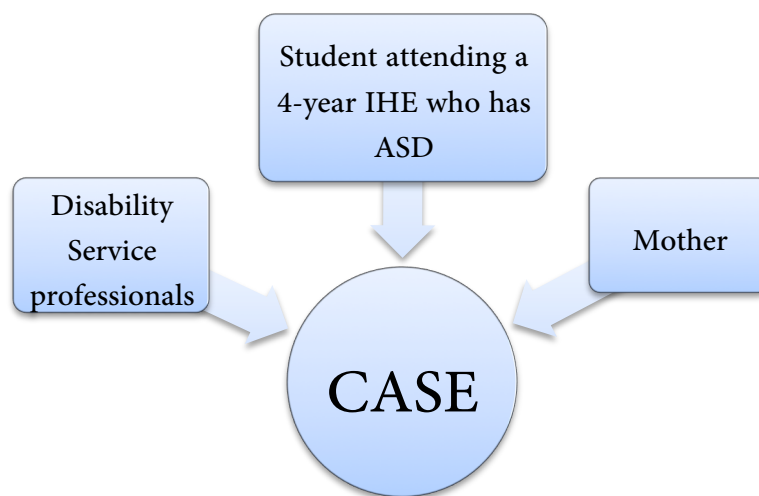
Study Design

This study used a qualitative instrumental case study design. “Case study is an in-depth description and analysis of a bounded system” (Merriam, 2009, p. 40). The focus is on “what” is to be studied, the bounded system. The aim in focusing on single phenomena, the case, is “to uncover the interaction of significant factors characteristic of the phenomenon. The case study focuses on holistic description and explanation” (Merriam, , 2009, p. 43). In this study, the phenomenon, “the what” is the ways in which a student with ASD was supported as he attended a four-year IHE. This study is an instrumental case study since the focus of the analysis is gaining an in-depth understanding of a specific phenomenon and the specific case plays a supporting role (Merriam, 2009).

Case study was determined to be the most appropriate approach for this study since it provided means of gaining the data required to answer the study questions through its inherent nature to investigate real-life “complex social units consisting of multiple variables of potential importance in understanding the phenomenon” (Merriam, 2009, p. 50). A second reason case study was selected was for the important role it can play in advancing a field’s knowledge base (Merriam, 2009). That is, the results of a case study are a rich and holistic account of a phenomenon, which “offers insights and illuminates meanings that expand its readers’ experiences. These insights can be construed as tentative hypotheses that help structure future research” (Merriam, 2009, p. 51). This feature of case study allowed the intended function of this study—to inform further research, and affect the practice of service providers—to be carried out.

The Case. In this study the bounded system, the “case” is comprised of data derived from the student attending a four-year IHE who has ASD, professionals from the office for Disability Services Office at the IHE who work with the student, and the student’s mother (see figure 3.1). This case design followed the recommendation of Dallas, Ramisch and McGowan (2015) that data be gathered from multiple stakeholders in order to gain a comprehensive view of supports and services received by students with ASD as they attend an IHE. Using a qualitative case design allowed not only for a comprehensive view of services, but a deep understanding of the ways in which a student who has ASD is supported as they attend a four-year IHE through multiple perspectives. The student is at the center of the case, this is in keeping with the concept of “Nothing About Us, Without Us”—the belief that, individuals with disabilities should be directly involved with issues pertaining to them (Dallas, Ramisch and McGowan, 2015).

Figure 2. Case Structure



Case Criteria. In order to identify a case that would provide answers to the study questions, essential case criteria were developed to guide the case selection process. These criteria directly reflect the purpose of the study and guide the researcher to an “information-rich” sample (Merriam, 2009). The essential criteria set forth for this study were 1) the student had to have a diagnosis of ASD that was verified by and received support from the Disability Services at the four-year IHE the student was attending at the time of the study, 2) the student was currently living in or had lived in campus housing, 3) the student was willing to participate in a multi-interview study and 4) the student agreed to sign releases that would allow the researcher to interview professional(s) from Disability Services at the IHE the student was attending, and a family member who could provide insight and understanding as to the student’s support needs. Once this criterion was met then the professional at the IHE and the family member would also need to consent to participate.

Case Selection. Intensity sampling, a type of purposeful sampling, was used in the selection of the case. Purposeful sampling is the deliberate selection of a sample based on its likeliness to be information-rich with respect to the purpose of the study (Patton, 2002). Intensity sampling is a type of purposeful sampling that is used in selection of a case that manifests the phenomenon intensely, but not extremely (Patton, 2002).

Case selection process: The following steps were taken in selecting the case for this study. First, directors of Disability Services at four-year IHEs that were classified as moderately or highly residential for undergraduate students were contacted via email. This correspondence served two purposes. First, it would be to gain consent from the

Director, should a student be selected from their IHE they, or other disability service professionals at the IHE, would be willing and able to participate in in-depth interviews regarding support for the student. Second, was to gain their assistance in actively passing on information to students that they serve who have ASD about participating in the study. This was of critical importance. It was from the only IHE that met with students to share the invitation to participate in the study (See Appendix A. invitation letter), rather than merely passing on the information, that the student was selected from (here after referred to by the pseudonym of Northern Coastal University (NCU)). Support in this process was essential since these types of tasks are often an area in which ASD impairs functioning, as it is primarily defined as impairment with deficits in social/communication. Only, IHEs that were moderately or highly residential were selected since one of the essential criteria to be met in the selection process was the student was currently living in or had lived in campus housing. The method of selecting the IHEs to contact was of convenience to the researcher (convenience sampling). Hence, the IHEs closest in proximity to the researcher's home were contacted first and expanded out until a case was selected.

The second step in the case selection process was to meet face-to-face with the student who was a potential study participant. The intent of this initial meeting was to share information with the student about the study, and gain information about the student to determine if they met the essential criteria for the study and would be an intense case. This researcher used the Student Consent form to guide the conversation about the study (see Appendix B). This researcher determined the student met the essential criteria: 1) student attending a four-year IHE has ASD, 2) has lived in campus

housing since he was a freshman, 3) old enough and willing to sign the consent to participate, and 4) allow the researcher to interview Disability Service personnel at the IHE he was attending, and a family member. Despite the offer of time to decide whether to participate (refers to the essential ethical principle of research stated in the Nuremberg Code) human participants freely volunteer to participate in the research (Steidman, 2006). The student indicated that he wanted to participate in the study at the time of the initial meeting. He signed his consent. His consent included allowing me to interview and, if pertinent, copy documents from Disability Services personnel he worked closely with and a family member. The student—will be referred to by the pseudonym Nathan—identified two staff at the Disability Services office at the IHE at which he was in attendance that he works closely with, and his mother as those to contact. Nathan felt that both the director and assistant director, hereafter referred to as David and Richard respectively, were both important in his support and felt that both should be interviewed.

Thus, the third and final step in selecting this case was to gain consent to participate from Director of Disability Services at NCU (pseudonym David), Assistant Director of Disability Services at NCU (pseudonym Richard), and Nathan's mother, who has been given the pseudonym Sandy. As with Nathan, the consent forms (see Appendix B) were used as a guide for the conversation about this study with David, Richard, and Sandy. All agreed to participate. Meeting with David and Richard was face-to-face. The introductory contact with Sandy was over the phone to accommodate her schedule, because she lived a distance from myself. The consent was mailed to Sandy prior to the phone appointment. In agreement to participate, Sandy sent the signed consent back me.

Data Collection

Gaining an in-depth understanding of the support that Nathan experienced as he attended a four-year IHE was the intent of the data collection. To accomplish this purpose, data was drawn from multiple sources of information. In-depth interviews were the primary source of data. Observations during the interviews, field notes and copies of documents from Nathan's file at the Disability Service Office were also part of the data collected. Using a qualitative case study design, the intent was to not simply gather data about the acts of support, but to gain an understanding of the context; how Nathan viewed support as he attended a four-year IHE and the role others played. Patton asserts, "People's behavior becomes meaningful and understandable when placed in the context of their lives and the lives of those around them. Without context there is little possibility of exploring the meaning of an experience" (Patton, 1989). (as cited in Seidman 2006, p. 17).

The in-depth open-ended interview was employed in this study. This interview style allows the freedom to "build a conversation within a particular subject, to word questions spontaneously, and to establish a conversational style but with the focus of a particular topic" (Patton 2002, p. 343). The three-stage interview approach for conducting in-depth interviews, presented by Seidman (2006) was used as a guide in developing the interview structure for this study. This model was selected for its intended outcome of gaining a rich understanding of the topic of study through deep exploration of the context in which it was experienced (Seidman, 2006). The first stage, establishes the context of the participant's experience, the second guides the participant to reconstruct the details of their experience within the context it occurred, and the third

has the participant reflect on the meaning their experience holds for them (Seidman, 2006).

A total of seven interviews were conducted—three with Nathan, two with David and Richard, and two with Sandy. Each interview lasted approximately 90 minutes. This data collection spanned a six-month period of time. Since data collection is emergent in case study research, careful consideration was given to the order that the interviews occurred (Merriam, 2009). The order allowed for data to emerge within respondent interviews, and across case respondents. That is Nathan, the focus of the study, was interviewed first establishing context of support. Then David and Richard, and Sandy's first interviews were used to establish context and reconstruct the experience of support. This was followed by Nathan's second interview—reconstruction experience of support. At this point all respondents were at the third stage, reflection on the meaning of the experience of support. There was no prescribed order for this final level of interviews to take place, thus they were conducted based on availability of respondents; Nathan, David and Richard, and the final interview was with Sandy. In order to preserve the exact words of the respondents, all interviews were audio recorded. This is the most common and accurate method of data collection during interviews (Merriam, 2009; Patton 2002). Field notes were recorded immediately after each interview as recommended by Merriam. (2009). As a final step at the end of one interview and in preparation for the next interview, as Merriam (2009) recommends, verbatim transcription of the interview was completed, prior to conducting the next interview. Merriam (2009) asserts that this step provides another means of generating insights about what is going on in the data. It allows you to plan for subsequent interviews according to what is emerging in the data.

This study was exploratory in nature, thus, it is important to allow for the emergence of data and to conduct preliminary analysis as the data was being collected (Merriam, 2009).

The above described data collection is summarized below in Table 2. Data Collection.

Table 2. Data Collection

Phase 1	Interview 1 Nathan: Establish context -Conduct interview -Write field notes -Transcription of interview -Revise interview guides		
Phase 2	Interview 2 David and Richard Establish context & reconstruction -Conduct interview -Documents from file -Write field notes -Transcription of interview -Revise interview guides	Interview 3 Sandy Establish context & reconstruction -Conduct interview -Write field notes -Transcription of interview -Revise interview guides	
Phase 3	Interview 4: Nathan Reconstruction -Write field notes -Transcription of interview -Revise interview guides		
Phase 4	Interview 5 Nathan Reflection -Write field notes -Transcription of interview -Revise interview guides	Interview 6 David and Richard Reflection -Write field notes -Transcription of interview -Revise interview guides	Interview 7 Sandy Reflection -Write field notes -Transcription of interview

During the design phase of this study, an interview guide was created for each of the seven interviews. Interview guides contained the content to be explored during each interview. When using interview guides the inquiry is not limited to, or by, the interview guides. “This format allows the researcher to respond to the situation at hand, to the

emerging worldview of the respondent, and to new ideas on the topic” (Merriam, 2009, p. 90). In following Merriam’s (2009) data collection procedures, prior to each interview, the guide for the interview was reviewed, and adjustments were noted based on prior data collection and transcript review.

Data Analysis

One attribute that sets qualitative research apart from traditional, positivistic, research is initial analysis occurs as a recursive and dynamic interplay with data collection (Merriam, 2009). In this study, as noted above in the data collection section, this process allowed for the emergence of data to guide the future data collection. However, the intense data analysis process began once all the interviews were completed and the last field note was written, and the raw data—recordings, transcripts, field notes and documents—were gathered and organized for ease of use (Merriam, 2009; Patton, 2002). Merriam’s (2009) inductive and comparative data analysis process, and the detailed description of the coding process presented by Saldaña (2016) were followed in analyzing this study’s data. The data analysis described below yielded a case profile and thematic analysis presented in the following chapter, Chapter 4 Findings.

Coding. The inductive process of coding was used to identify themes in the data. Coding is the critical process used in qualitative research to move from data collected, to the explanation of its meaning (Saldaña, 2016). It is the process of sorting and organizing data. A code is a “word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language” (Merriam, 2009, p. 176).

Oral, open, and In Vivo Coding were used in first-cycle coding. Oral coding is repeatedly listening to the interview audio recordings over several days to gain intimate knowledge of their contents (Saldaña, 2016). Oral Coding allows the researcher to stay as close to the participant lived-experience through hearing his/her words in his/her own voice: the researcher is “deeply embedded in the literal voices of participants, allowing nuanced inferences and interpretations of vocal tones, rates, subtexts, and the like (Saldaña, 2016, p. 74). Open coding is an open-ended approach to coding data, that is, the researcher does not have any predetermined codes or categories when starting data analysis (Saldaña, 2016). Open coding allowed for the unknown to emerge in that this study is exploratory in nature. In Vivo Coding, the final approach used, a word or short phrase from the document being analyzed, as the codes (Saldaña, 2016). This approach was selected due to the desire to capture the respondents’ exact words.

Second-cycle coding was the next step. In this cycle Pattern Coding was used. “Pattern Coding develops the ‘meta code’—the category label that identifies similarly coded data. Pattern Codes not only organize the corpus but attempt to attribute meaning to that organization” (Saldaña, 2016, p. 236). Through this process this researcher was able to reduce the codes and categories identified in first-cycle coding categories to the six themes presented in the following chapter.

Crafting the case profile. The case profile was crafted between the first-cycle and second-cycle coding. Thus, in addition to assigning codes during the first-cycle, passages of interest, relating to the construction of Nathan’s profile were highlighted. This was not a separate process from the coding, but integrated as the data corpus was

mined multiple times. The marked passages were compiled into one document in chronological order. The critical passages were identified with the intent to present a deep, richly descriptive, holistic portrayal of Nathan's support with the context necessary to understand the case and afford the reader to vicariously experience the case (Patton, 2002).

Theoretical lenses

There are two interconnected lenses that have been used in the analysis of this study. First, as evident by the methodology employed in this study, is constructivism. This, the broader lens of the study guided the research practices from design to interpretation. Constructivism postulates that "reality is socially constructed, that is, there is no single, observable reality. Rather, there are multiple realities, or interpretations, of a single event. Researchers do not "find knowledge, they construct it" (Merriam, 2009, p. 8-9). Using the constructivist paradigm, the researchers seek to gain a deep, rich understanding of how people interpret their experiences, and construct their worlds. It seeks to find what meanings people attribute to their experiences (Merriam, 2009).

The second lens, The Interactional Model of Disability, is a more focused lens relating to the specific area of study. The Interactional Model conceptualizes disability as "a complex and multifactorial phenomenon that results from the interplay of individual factors that relate to impairment and social factors. Disability is "the outcome of the interaction between individual and contextual factors—which includes impairment, personality, individual attitudes, environment, policy, and culture" (Shakespeare, 2006, p.

58). The Interactional Model of Disability takes into account the inherent nature of impairment in a natural and matter-a-fact approach. It is intrinsic factors a person brings in combination with the societal culture, both broad and specific to the situation that constructs the experience of disability (Shakespeare, 2006, 2013). This lens was used through all phases of this study, to view the interplay of different factors that contributed to the ways in which Nathan was supported while attending a four-year IHE, and how he experienced support.

Role of the Researcher

The researcher is the primary instrument in data gathering, analysis and interpretation process in qualitative research. The use of a human instrument allows for infinite adaptability in identifying and targeting information, unlike physical instruments, which can only measure particular factors (Patton, 2002; Merriam, 2009). This means that data are mediated through this human instrument through all phases of data collection and analysis. For this reason, it is important that the researcher identify his or her interest in the subject and examine it to make sure that the interest does not infuse bias, or prejudice (Seidman, 2006).

Researcher Bias. It is important for the researcher to put fourth their background and what their experience and beliefs they hold as the instrument of the research. Thus, I have over 30 years of experience working with, and developing support services for, individuals of all ages who have impairments. A majority of my experience has been in the not-for-profit social service delivery system for individuals approaching and in their adult years. However, my most recent experience is as a Special Education Resource

Specialist in Title One public schools, serving students in kindergarten through eighth grade. Through these experiences I have learned the value of varying points of view when developing support, and the important roles different individuals play in the life of a person with impairment. Perhaps, most importantly, and often overlooked, is the perception and experience of the person with the impairment. In the early 80s, as the disability rights movement was under way, a slogan was used: "Not about us without us". I believe that this was and should continue to be practiced when developing ways for individuals with impairments to gain access to services and be supported. For these reasons, the student, Nathan, is the primary component of this case study.

My philosophical frame is in alignment with the interactional model of disability. I have found through my experience as a service developer and provider, a researcher and of having impairment and resulting predicament of disability, there are many compounding, inherent and external factors that lead to the experience of disability. It is not a static event. I bring to the study an understanding of the experience of disability. While I have a personal understanding of disability, I am limited in that my understanding of ASD is from a professional perspective, as the nature of my impairment is visual.

Finally, through my professional experience I have gained rich knowledge from parents of children with impairments. This coupled with my own experience of being a parent of a student with learning disabilities provides me with a foundational understanding of parental experience.

Data Credibility and Consistency

Credibility. To reduce researcher bias and maximize credibility, “the correspondence between research and the real world” (Merriam 2009, p. 214), in this study, triangulation and reflexivity were used to ensure credible results.

Triangulation is “using multiple sources of data means comparing and cross-checking data collected through observations at different times or in different places, or interview data collected from people with different perspectives or from follow-up interviews with the same people” (Merriam, 2009, p. 216). This study utilized triangulation in two ways. First, the three-step interview process used with participants enhances the accomplishment of credibility through placing the participant’s comments in context and the use of multiple interviews, over time allows for a means of evaluating the internal consistency of individual responses (Seidman, 2006). Second, was the use of multiple sources of data, which allowed for corroboration data through the convergence of multiple sources of data (Mariam, 2009; Patton, 2002).

Reflexivity is critical self-reflection as researcher, human instrument (Merriam, 2009). The researcher must share his/her biases, to provide the reader understanding of how the researcher’s values and expectations influence the study (Merriam, 2009; Patton, 2002). Researcher Bias is presented above.

Consistency. Consistency refers to “whether the results are consistent with the data collected” (Merriam, 2009, p. 221). That is, given the data collected, the results make sense, or are the results consistent with the data collected (Merriam, 2009). The triangulation and reflexivity strategies discussed above, also are strategies that strengthen the consistency of a study. Thus, triangulation and reflexivity were used in an effort to

maximize consistency in the study. Also, used was researcher journaling, or an audit trail.

Assumption

The following are the assumptions of the study. First, it is assumed that the study participants responded honestly and to the best of their ability. It is assumed that the student has been accurately diagnosed with ASD thus, meeting the criteria for the study.

Limitations

The following are the identified limitations of this study. The first limitation of this study is that potential participants were limited to those who self-identify as having ASD and request services from the Disability Service at the four-year institution of higher learning they are attending. One of the biggest obstacles to serving students with ASD in postsecondary education is the lack of students identifying themselves to Disability Services (stated by Dr. Thierfeld Brown during a phone conversation (October 16, 2014). Many students choose to "pass." Passing is the act of people concealing their impairments to avoid the stigma of disability and to pass as normal. ASD does not manifest physical attributes that can easily identify the individual as having this impairment. It is what is referred to as a "hidden disability." Thus, based on the criteria of this study, the participant must be a student receiving Disability Services from the IHE. There were students at the institutions selected for this study who have ASD and would not have been considered for this study.

A second limitation identified in this study is an inherent quality that is known to the researcher who selects case study research, is that it is limited to analytic

generalization. As Yin states, “case studies, like experiments, are generalizable to theoretical propositions and not to populations or universes (analytic generalization) and not to enumerate frequencies (statistical generalization)” (2009).

Summary

Presented in this chapter is the methodological process for this case study. The case was described as an exploratory instrumental design. The case is comprised of data derived from interviews with Nathan, a student attending a four-year IHE who has ASD, David and Richard, professionals at NCU Disability Services at the IHE, and Sandy, the student’s mother. The three-phase in-depth interview approach was used in this study to gain a deep and rich understanding of the ways in which a student with ASD was supported as he/she attended a four-year IHE was presented. Data was analyzed through coding and the process of crafting the case profile was described. The two theoretical lenses that guided this study, constructivism and interactional model of disability, study data credibility and consistency, and study assumptions and limitations were provided.

The results of this study will be presented in the following chapter as a profile and rich description of the themes.

Chapter 4: Findings

Introduction

The findings in a qualitative case study contain rich, thick description, to allow the reader to vicariously experience the phenomena under study. That is to allow the reader to experience something they would not otherwise encounter (Merriam, 2009). Presented in this chapter are the findings that emerged through analysis of the raw case data. The data that comprised this case, bounded system, include: verbatim transcripts of seven interviews: three interviews with Nathan, student; two interviews conducted jointly with David and Richard, Director and Assistant Director of Disabilities Services at North Coast University (NCU) respectively; and two interviews with Sandy, the mother of Nathan—and copies of documents in Nathan's file at the Disabilities Service Office that verify and describe Nathan's disability and needed accommodations. The names of case participants and the university are pseudonyms assigned by the researcher to preserve the anonymity of case participants.

The purpose of this case study was to gain an in-depth understanding of the ways in which Nathan, a student with Autism Spectrum Disorder (ASD), was supported while attending NCU. The intent in conducting this study was to add to the scant body of knowledge on this topic, to inform further research, and to influence the practice of service providers who work with students with ASD and attending IHEs.

The constructivist lens was one of two lenses used in the analysis of the data. Constructivist view reality is socially constructed. Using this paradigm during data analysis allowed for the emergence of meaning, to gain a deep rich understanding of how Nathan, David, Richard and Sandy interpret the experiences of Nathan's support. Using this lens during data analysis, this researcher co-constructed, with the respondents, the experience of support. Researchers do not "find" knowledge, they construct it (Merriam, 2009, p. 8-9).

The second lens, Interactional Model of Disability put forth by Shakespeare (2006, 2013) was the theoretical lens that was used in analyzing the data regarding disability. This model identifies disability as an interaction between individual and structural factors. Shakespeare explains:

The experience of a disabled person results from the relationship between factors intrinsic to the individual, and extrinsic factors arising from the wider context in which she finds herself. Among the intrinsic factors are issues such as: the nature and severity of her impairment, her own attitudes to it, her personal qualities and abilities, and her personality. The contextual factors influence these intrinsic factors: impairment may be caused by poverty or war; personality may be influenced by upbringing and culture, etc. Among the contextual factors are: the attitudes and reactions of others, the extent to which the environment is enabling or disabling, and wider cultural, social and economic issues relevant to disability in that society" (2014, p. 74).

Hence, in-depth interview approach used in this study not only provided the context sought to gain a deep understanding of Nathan's lived experience of support, it also provided the context to understand his disability.

This chapter will present the findings of this analysis. First, a case profile will be presented, and then the themes that emerged.

Case Profile

Nathan is the primary character in this story. Interactions, interpretations and experiences with David, Richard and Sandy are interwoven into the story to provide the deep texture and contextual descriptions. Information about Nathan's early years, before attending NCU, provides important contextual information relating to understanding of his experience of support while attending NCU.

Background context. Nathan, at the time he was interviewed was 21 years old and in his third of anticipated 5 years at NCU, to earn a Bachelor of Science degree in computer engineering. NCU is a small liberal arts university in the northwestern United States.

Road from Birth to College. Nathan's father was in the military. As a result, his early years were spent moving between Germany and the United States. When Nathan was in fourth grade his family moved to the Northwestern United States, and settled in that location (dad would go out on assignments). Nathan remained there until he moved to college, and returns home during summers. His home, while not in the same town as NCU, is nearby. Nathan's immediate family consists of his mom and sister to

whom he is close, but states with sadness in his voice, in regard to his relationship with his dad:

He wouldn't really make a connection. So, I eventually had to try to make the connection with him. And it didn't really work. My dad never understood. Like, he never really understood. He just thought like you know "you're just screwing up you know just be normal, be normal."

ASD identification and effects. Sandy, who was 26 years of age when Nathan was born, shared that there were communication and behavioral events in Nathan's early development that were related to ASD, and "a lot of challenges that I did not know until later on had to do with autism." She shared that Nathan only spoke very few words until he was 4 years of age. Sandy stated, "He wasn't talking. He was having tantrums from 18 months until he started verbalizing....Once he began verbalizing we were ok." Sandy also recounted that when Nathan was young, he didn't like to go anywhere:

Transitioning was a real challenge. I would just have to sit down like on the edge of a curb and wait for him because he was like a little octopus when trying to get him into a car. He was all hands and feet grabbing on to the side of the car so he would not have to go into the car seat. I just couldn't do it. I just couldn't struggle with him, I had a baby, his sister, with me. So we'd just wait him out until he got into the car.

Sandy's oral animation in telling of this event, and the laugh that accompanied this story, told perhaps even more than the words. It said in hindsight it's funny; a release of I got through that, but at the time required a great amount of patience. I have

heard this in the voices of many parents, including myself. Sandy has been very committed to Nathan's success as a student and person and often put his needs first.

Other behavioral features of ASD that Nathan exhibited were compulsive hand washing, fear of germs, not wanting to be around people, not wanting to be hugged or touched. He was very particular about his things. He had collections of things and would get frustrated if things weren't organized the way he wanted, yet he was not able to organize them himself.

Nathan's early education was riddled with challenges due to both the inherent features of his impairment, and the extrinsic environmental responses to him. Nathan went through special education testing while on the military base in Germany. He was identified as needing speech services, and since he had anxiety issues, he was identified as emotionally impaired. Challenges including teachers saying he was not learning anything and Nathan shutting down in a chaotic third grade. The third grade class was so chaotic Sandy left a substitute-teaching job to home school Nathan. This got him caught up and ready for fourth grade in the US, where he returned to the classroom.

Once in school in the community where Nathan's family had decided to settle, school was good for 2 years: he had good teachers. During this time Nathan was in general education and received Special Education Speech services. "Then in sixth grade his teacher wanted him out! He got really good grades, but she focused on him. It was a really horrible situation. It was traumatic for all of us hearing the things that were said to him," Sandy stated. She explained that after sending six letters to the district's superintendent with no resolve, she finally wrote to the Office of Civil Rights (OCR). The district was found guilty of harassment, and failure to meet the districts offer of a

free and appropriate public education (FAPE). The outcome of this process was Nathan was moved to another school in the district and it was recommended to have Nathan tested by a local agency to determine if he had ASD. This testing resulted in a diagnosis of high functioning autism. Sandy explained that the diagnosis did not really change things. "I already had found ways to accommodate my son, beyond the professionals. They had me going in all different directions. And some of them were really incredibly backwards."

Nathan went through high school with a 504 plan. High school was a positive experience. Nathan got the needed academic support, including continued help from his mom. He excelled academically. He continued to have some struggle to develop social relationships. And, at times, as Sandy shared this was further complicated beyond his autism due to being biracial, Caucasian and African American.

When asked about his early experiences regarding his diagnosis of ASD. Nathan recounted,

I found out maybe officially in fourth grade....I just remember I got tested because I was struggling in class, and my mom noticed I would obsess over problems. Instead of skipping one I didn't know, moving on, I would just stay on that one, I don't know for 3 hours, and just stare at it until I completed it. So, she could tell that's not normal.... I had always been different than from the other kids. I'd see this guy who specialized in helping with autism. He'd tell me, this isn't normal. Why don't you do this instead? I would think why would I do that when I can play video games? I used to use video games a lot to not feel bad. It was really hard. I didn't want to recognize it. I wanted to assume it was normal

to not go anywhere, staying home playing video games, and not having any friends to talk to or play with. But, eventually I could see he was right. I didn't want to feel like that anymore. I didn't want to feel different. I wanted to have the same interactions as the next guy. I have always felt kind of bad about it. In fact it makes me feel sad just thinking about it.

Nathan's voice became quieter and solemn as he shared his experience.

Nathan also explained how the social deficit features of ASD impacted his school experience. In looking back he could now identify how some of these issues impacted others. He explained he didn't understand how people felt when he was young. Things were concrete. Questions provided answers. He gave the following example.

I had teachers that would say I was disrespectful of their authority, or I was being rude when I was asking serious questions. For example, a teacher may say my husband left me, and I asked, why? He doesn't like you anymore?

While Nathan has come to learn more about social norms, and why such questions would have bothered others, other situations still remain a mystery to him, such as the situation with his sixth grade teacher. He recalled:

There was one teacher who hated me so much because I got As. I feel like they thought I was annoying. So, me getting As, putting out the effort to do good, made them hate me? I don't know. It has been a really hard experience. I had to leave my elementary school because the teacher discriminated against me.

Nathan also struggled with other students not following rules. He would get very upset if peers tried to get answers from him.

IHE experience. When it was time to select a college, Nathan and Sandy visited many IHEs on the west coast, some far, some near. Nathan was in search for an IHE that met his academic interests and an environment that was comfortable for him given his ASD. NCU rose to the top of Nathan's list. Sandy, knew Nathan wanted to go to NCU, however, was not sure if they could afford a private college. Nathan felt comfortable at NCU because of the smaller classes, fewer people on campus, and he liked the fact that he would be able to get in touch with professors one-on-one. Nathan explained:

I didn't feel like, just one little pebble amongst a bunch of rocks all around me.

All the other schools had this thing that made me feel overwhelmed—the classroom size and the competitiveness. Some schools weed out all the weak links as soon as possible. I wasn't ok with that. It sounded really bad.

Nathan and Sandy visited the Disability Services office at each IHE they visited. However, the Disability Services were not a determining factor in selecting an IHE.

Nathan at NCU. Nathan received a full academic scholarship and was able to attend NCU. Transitioning into the college held many new experiences for Nathan, as for all young adults forging towards independence. However, for Nathan these experiences were more intense due to having ASD. At times this made some of what most students roll through, huge anxiety-laden experiences, particularly in his freshman year. As Nathan put it, “freshman year it was so difficult. It was so scary. It was overwhelming, just freaking out so much.” Nathan had a strong support system to help him get through the difficult times and develop the skills needed to independently navigate situations that would arise in the future. This support consisted of Nathan's mother, Sandy, and David

and Richard from the Disability Services office at NCU, working in tandem, along with his faculty advisor and counselor.

Disability Services at NCU. Despite its small Disability Services department, the support Nathan received from NCU Disability Services was comprehensive in meeting Nathan's needs associated with ASD. Support went far beyond academic accommodations. Social communication, and sensory needs associated with Nathan's ASD were addressed in all facets of his college experience. Nathan found that David and Richard were extremely dedicated professionals that were invested in his success. As Nathan put it, "I really lucked out!" David and Richard are very dedicated professionals. They are willing to go far above and beyond to meet the needs of students, and be supportive of faculty and staff in their interactions with students with disabilities. They are very much in sync with each other's thinking. David has worked as Director of Disability Services since 2007. Richard came aboard as a graduate assistant in 2011 while completing his master's. His position evolved into an assistant director position as the demand for services grew about a year prior to this study.

NCU in accordance with the provisions of the American's with Disabilities Act requires documentation of disability by an appropriate and qualified professional who can verify and is capable of describing the condition when determining a student's eligibility for accommodations. Nathan's psychological report indicated he has a diagnosis of high functioning autism, generalized anxiety disorder, Turret's and an auditory processing disorder. The psychologist report also stated:

He has difficulty concentrating and focusing. His anxiety and autism negatively impact his interactions with others. When sleep is good and student has ample

time to complete academic tasks, the student can function very well. Single living arrangement would optimize the student's ability to sleep, manage his anxiety and function well. Has significant test anxiety requires additional time to process information and respond to test items.

It was upon this document that Nathan was afforded accommodations and access to the Disability Services at NCU.

The summer prior to Nathan starting at NCU Sandy was in contact with David numerous times to figure out what kind of accommodations would be available to Nathan. The first step was the arrangement of what would become a critical physical accommodation for Nathan enabling him to take part in the full college experience including living on campus—a single room. David stated this was a common accommodation for students with ASD. “If a student on the spectrum wants a single room, we do everything we can to make that happen.” A second step was arranging for Nathan and Sandy to come during the summer and view his room and residence hall so that he could begin adjusting to where he would be living. Viewing an exact room was typically not allowed by NCU, but in Nathan's case deemed necessary. David and Richard had planned to start meeting with Nathan and make him feel comfortable during orientation and prior to classes starting. David recalled:

It was a delicate hand-off and I would say mom was very anxious. She was looking for a source that she could rely on for some of the problem solving and a place where she could help encourage him to go when he was having challenges and have that trust and faith in the place as opposed to just sending him somewhere that would he not get support and kind of backfire. She needed to

find a resource or a connection to replace her, or she wouldn't feel comfortable with fully stepping out of the equation, so he could fully experience college as a college student.

Richard added, in regard to providing support immediately upon Nathans arrival to campus, "I think that is what possibly created the level of comfort for both the student and his mom."

Academics-ASD impact and support. Features of Nathan's ASD have presented him with challenges and strengths in his academic pursuits. As part of the standard intake process, David and Richard reviewed prior academic accommodations used by Nathan, and worked with Nathan to determine what would be carried over and used at NCU. David explained, "The first semester is essentially a trial and error period". Nathan's Initial academic accommodations included extra time on quizzes and exams (time and one half in an environment with reduced distractions), permission to record lectures, be provided guidelines and instruction for complex assignments in advance to allow additional time for completion. Over the 3 years, Nathan's accommodations have remained fairly consistent. Some additions included, provide copies of the professors notes or lecture outlines if appropriate and available, a note taker for certain classes and his extra time for quizzes and tests was increased to double time. However, Nathan, David and Richard all concurred that the primary accommodation that Nathan consistently uses is the double time on test and quizzes, in a reduced distraction environment. Nathan also explained, "When I am taking a test, I bring a watch so that I am seeing how many minutes I am actually spending, because I can't feel time."

A letter is sent to each of Nathan's professors informing them of his accommodations at the beginning of each semester, along with information that may assist them in working with students with ASD.

In addition to its impact on test taking, Nathan has had other time-related challenges. Much like when he was little, Nathan would perseverate on his Math homework when he started at NCU. Robert explained, that for many students, Nathan included, part of the transition coming from high school, where you have a consistent schedule, is learning to manage time and an inconsistent daily schedule. David explained:

He would sit down and spend too much time on one subject—calculus homework, six hours, then he would be overwhelmed because he had other homework. So, whereas other students we help getting started, we helped Nathan to get finished.

Time Management was one of the areas that Richard coached Nathan on. Nathan learned to create a strict schedule for completing homework, which would not allow him to work too long on one topic. It also, included helping Nathan to seek out additional resources through the engineering program, sooner rather than trying to do it on his own when he needed additional assistance. Nathan reported that this approach was needed and very helpful at first however; at this time he only has to rely on a strict schedule when he has a very demanding schedule for work completion.

Another impact of issues relating to time was identifying an appropriate workload each semester. Nathan could not manage the same load of classes that was typically completed each semester by students in the Engineering Program. Nathan stated

Richard helped me realize a more realistic goal for classes. I can't handle five classes at once, really a lot of pressure. It's too much, especially if they have laboratories. I like learning and taking my time so less units is more ideal, so I can actually focus on the subjects.

The Engineering Program at NCU is a four-year program. With the guidance Richard provided on course-load, Nathan set forth a plan for completing the program in 5 years. This was not a concern for Nathan since at many universities Engineering is a five-year program. Also, his scholarship covered 5 years.

During class lectures, Nathan's auditory processing deficit and difficulty with social interactions at times pose challenges. When there is not enough visual support along with oral lecture, Nathan at times records lectures, or requests a note taker. The latter is rare. Nathan discussed how his uncertainty as to when to interject questions and when not to interrupt is difficult for him, and distracts him from the lecture. He explains with great frustration, yet with humor:

Timing, when to ask a question and when not to interrupt. It's so nerve-racking. It disrupts my learning because I obsess about the question. It is hard for me to focus on what is he talking about right now because I don't want to forget the question. It is really hard, especially when it is a really big question, and I really want that answer. That happens so often it's not even funny. I hate that!

Nathan does rely on going and talking to professors during their office hours to "get help." However, initially Nathan needed some coaching to be able to send emails to teachers and in some cases support in how to approach them.

In terms of sensory aspects of ASD impacting Nathan's academic experience, things in the environment can be distracting to him, and cause him to lose focus during tests. This is why he requires a reduced distraction environment for testing. He also is at times bothered by florescent lighting, and may wear sunglasses in class.

While ASD has resulted in need for accommodations, and to take more time to complete the program, it also has some features that Nathan feels helps him excel in academics, and specifically computer programing. He is a straight A student. Nathan explained how his ASD aided in his academic success:

My autism gives me patience. I can look at something for a very long time, where some people will just give up. I have more endurance to work harder than other people... I am able to program things that people don't think about... I use it for learning programing, memorizing the little things. That's something that is really cool about somebody on the spectrum if they like something they know it better than anyone else. They become the best. And that is what I try to do. I don't want to just be an engineer. I want to be one of the best engineers.

As will be discussed below, Nathan at times has difficulty with relations and socializing, however this is not the case during academic endeavors. Other students value his skills. Nathan stated, "I am able to engage people by working in groups and I can coordinate things." He reports as long as it is related to academics, "I am fine communicating."

Social Communication, student life -ASD impact and support. Nathan possesses a great amount of self-awareness about his social communication deficits. And has worked extremely hard to not let them hold him back. Nathan stated, "I think I have

worked harder at socializing than anyone else, because I knew I had a problem.” Despite his awareness and efforts to improve, Nathan faced many challenges related to his social communication characteristics associated with his ASD, while at NCU. These situations where at times very overwhelming, to Nathan however, they also provided opportunities for him to further grow and develop his skills.

Freshmen year presented huge challenges for Nathan in the area of interactions with others. David and Richard, anticipated these types of challenges based on intake information provided in his verification of disability paperwork, speaking with Nathan’s mom, and Nathan’s self-report. David stated, “We knew we really needed to create a rapport and attempt to create this welcoming environment, so that he would at least come here and let us know he is having a challenge.” Challenges ranged from not knowing how to interact with peers, academic issues, and issues of activities of daily living. However, it was the inability to know how and who to speak with that complicated the events. Richard had weekly coaching appointments with Nathan. This allowed for him to address issues that were of immediate concern, and work toward the development of a trusting relationship in which Nathan would feel comfortable coming directly to Richard, or David. When Nathan started at NCU, he would tell mom about problems, and mom would call David or Richard. In time the shift did occur.

Nathan expressed a strong desire to have typical peer interactions throughout the interviews. Attaining this at NCU has posed many challenges. Freshman year was the worst socially for Nathan. He wouldn’t go out very much, and would stay in his room and play video games, much like when he was younger. Sophomore year brought more opportunities for socialization. Nathan shared, “sophomore year was a little better. The

whole dorm floor was nothing but engineers. It was our own little community. It was really fun.” Fellow engineers are the easiest peers for Nathan to communicate with since they share interests, and workload...He could relate to them. Nathan’s academic strengths served as a conduit of social interaction in the dorm. Students would go to Nathan’s room for help. Nathan said in a proud manner, “I would show them all these problems on my white board.” However, as with all social interaction for Nathan, he had limits on how much he could handle, so at times he did not respond to the knocks on his door.

In regard to outside of the dorm socialization Nathan explained,

I don’t really go out and have a good time. Or, what other people identify as a good time. Parties, dances, stuff like that.... I have gone to parties, they are overwhelming and it is just uncomfortable for me. I usually just go there and watch strangers have a good time. While I’m standing awkwardly pretending to enjoy the drink in my hand, yah, woof, this is so fun!

He further explained typical events like basketball games were not appealing to him either. He stated, “I would rather be working on homework and stuff. But it makes me feel bad that I don’t interact with people like the next guy.”

Nathan continued to pursue finding a social niche at the end of sophomore year, as he felt isolated; he did not know a range of people. He desired greater connection to people. Nathan explored a variety of fraternities and joined the professional Engineering fraternity since he could connect with the members through mutual interests. Nathan explained,

The fraternity helps. I joined because it forces me to go to social events. Which is nice sometimes, and other times it's not nice at all. Like when there are back-to-back-to-back mandatory events....There is no time to recover. I have limits... I am forcing myself to do things that scare me or make me feel insecure. It becomes overwhelming. It takes energy. It takes a lot of energy to be able to have social interactions. I only have a certain amount of energy. It is physical, like a muscle and it gets strained sometimes.

Nathan chooses not to disclose that he has autism to the fraternity. This has created many challenges, for he does not explain why he is not at all the events, or able to maintain socialization through the events. In fact, Nathan does not disclose his ASD to any peers.

In addition to the one-to-one coaching that supported Nathan through many different social predicaments, he was also in the first cohort of students with ASD to participate in a social group. The social group is a partnership with the counseling center and Disability Services. This group has weekly meetings for students to have discussions around specific topics relating to socialization related to ASD. Nathan has also accessed the services from counseling department. And above all, Nathan's mom has been a huge emotional support, and has assisted him by initially being the communication link between himself and Disability Services and being available by phone to talk to 24/7.

Activities of daily living ASD impact and support. Nathan experienced challenges due to behavioral features of ASD, and his anxiety disorder, particularly in his freshman year. These challenges manifested in predictable areas such as the predicament of being in a shared living space of the dorm, and unpredicted tasks related to attending college. It was the later that caused Nathan in his words to "freak out."

From the combined perspectives of Nathan, David, Richard and Sandy, “freak out” meant, a situation arose, particularly something that was new to the college experience, or due to being in a new environment, and became a huge obstacle to moving in any direction. Nathan was stuck! He was consumed by the situation, paralyzed, unable to move in any direction, and not knowing what to do.

One example that occurred during Nathan’s first semester at NCU is as follows. The window for class scheduling for spring semester opened. Nathan was not used to having to select his own classes. As he explained, “In high school it was easier. They tell you, you have to take this, and you get to choose this. You don’t get a lot of choice.” Choosing classes seemed to come out of the blue for Nathan he was overwhelmed with anxiety.

I didn’t expect to have to choose my classes before my classes were even finished: I was thinking of my testing. I was freaked out, how could I think of my classes while I am already in classes? It was really bad.... I was so freaked out there were so many options,” Nathan expressed, still with a sense of stress in his voice as he recalled. Nathan contacted Sandy when he was ”freaking out.” Sandy, not knowing how to advise him, contacted Richard. Nathan recalled that Richard came over to his dorm room. He helped Nathan both with the scheduling, and the more immediate need, the anxiety Nathan was experiencing. Having had that experience and several semesters behind him Nathan stated, with comfort,

Now I work with my advisor, we know what kind of class load I like. I’ve learned from experience that I am kind of in the hang of it and my advisor knows

me now. And we are able to get things going. But, freshman year it was so difficult it was so scary it was overwhelming just freaking out so much.

This situation was one of several that all respondents independently brought up with presentation that it was a very intense situation for Nathan.

A more predictable area of challenge for Nathan was regarding the shared living space of the dorm. As noted above, Nathan was afforded the opportunity to have a single room. This resolved a host of potential barriers that could have prevented Nathan from being successful in living in a dorm, and his desire for gaining the full experience of college. With those issues behind him, Sandy stated, “The bathroom was going to be the biggest challenge for him.... He had issues about things touching things and getting germy.” Since this was a predictable area of concern Sandy developed a system that would prevent anything from touching the ground. Sandy explained,

I sewed elastic onto every towel and washcloth, and Baugh camping hooks that would hook on to the shower pole so that nothing would touch the floor or get knocked down on the floor.... He had a sink in his bedroom. It was an old, single with a sink. Which I think helped tremendously. I am not sure how he got over using the restroom because, I just, that kid would hold until he would come home when he was in high school. So, somehow he got past that in college.

Having the insights into challenges that ASD may present, Richard provided support in this area. Nathan shared that Richard had acquainted him with a variety of restrooms on campus, so should he not feel comfortable using the restroom at his dorm, he would have other options. Thus, with the support of Sandy and disability services, David and Richard, despite in Nathan’s words, “It was pretty bad freshmen year, living in the dorm,

it was horrible.... it was so disgusting.”: Nathan was able to remain in the dorm for his freshmen and sophomore years. For his third year Nathan chose to move into an NCU apartment, still on campus. Students were required to move out of the dorms in their third year. He lives by himself and has his parrot for companionship. Nathan likes living in the campus apartments since he is still on the meal plan and there are still rules about residents’ behavior, governed by NCU.

Reflection. Nathan in reflection on how his experience has been at NCU states, “Academically it has been going great, fantastic!” He is a straight A student. In regard to social life:

Honestly, I think it would have been worse at a bigger school. Way worse. I probably would have felt more isolated at a bigger school. My social life hasn’t been as bad as I thought it would be. I have a group of engineer friends. But, there are still times when I think I don’t really fit in around here, especially with the fraternity, Nathan stated.

Nathan also is very grateful for the support he receives, and does not think he could have gotten this far without it. He depicts a tower.

My mom is the slab or the land. I wouldn’t have been able to build anything without her.... David and Richard, I see them as structure, the support beams. They are the foundation, helping me build the tower. They are solid. Because without them, I don’t think I would have been able to get this far. David and Richard helped me to get to the point where I don’t need their help as much anymore. I am able to build some levels myself. My advisor is like the tools

to build the structure; how I want to build my tower, the schematic. She helps me get the blueprints out nicely- where do I want my life to go.

Themes

This section will present the themes that emerged relating to Nathan's experience of support at a four-year IHE. The data from all seven interviews, field notes, and documents; that is the entire data corpus for this study, were analyzed as a unit through the process of coding (see chapter 3 for details on coding process). Six themes emerged from this process: ubiquity of disclosure, proactive early nonacademic support is imperative, coaching from freak-out to function, support from mom invisible, but essential, individualized approach by dedicated professionals, and textures of Nathan's autism.

Ubiquity of disclosure. The issue of disclosure is a ubiquitous part of Nathan's experience as a college student who has ASD. It is the interplay between Nathan's perceptions of himself, his desired life outcome - intrinsic factors, and the reactions of those in his environment and the more global societal view of ASD - extrinsic factors that shape Nathan's determination of to whom he discloses he has ASD.

Nathan does not disclose he has ASD to his peers at NCU. Among the reasons for this decision are current cultural responses to autism as an invisible mental impairment, past experiences of discrimination and his desire to be treated the same as anyone else.

Nathan feels there is a lack of acceptance of individuals with ASD by society, particularly young people. He explained, "Right now 'autistic' is being used as a synonym for stupid." The phrase, 'what are you autistic,' is commonly used in a

derogatory manner in our society. He has encountered this in everyday conversation, on line communities such as Reddit, and even in the movie *21 Jump Street*. Nathan felt when it comes to hidden disabilities, that even though his peers were open to other forms of diversity, they do not understand, or have tolerance for mental health impairments. They're less sensitive than they are toward other issues of diversity like homosexuality. "They don't get the invisible disabilities, no! The physical disabilities, yah!"

Sandy shared that Nathan keeps his ASD hidden, although it, in some situations would make things easier if he did disclose his disability, particularly in regards to challenges he is going through with his fraternity. However, she respects his decision. She stated,

He feels like society especially young people classify autism as some type of mental retardation. Like, something's wrong with you if you have it. He doesn't want people at the college to know he is a disability student... he is afraid it's going to change the way that, um his peers view him. It will make him undateable – chuckle!

Even if he is faced with negative consequences and extreme stress Nathan will not disclose. Nathan's mother conveyed the following situation that occurred with Nathan's fraternity.

Nathan had a problem with the fraternity. He did not want to expose his disability; they didn't know he had a disability. But the things that they didn't like about him were all connected to the disability. It was a very sensitive situation, because he was being penalized because of some things that weren't fair and so he could have used his disability to have an easy out, claiming this is why.

Nathan said, "I should not be treated like this. I should not have to tell them what my disability is. I am going to just ride this one out, and what happens, happens." He got through that and he is still in the fraternity, but after that event it wasn't the same. I think it kind of scarred him a little bit. He is still in it, but I can't say he wants to continue.

David and Richard also encouraged Nathan to talk, and presented the option of sharing with the fraternity board in confidence, but Nathan was adamant about not disclosing that he had ASD to anyone in the fraternity because he did not believe it would stay confidential. David stated,

If he had gone to the leadership team and said, I want to share with you, I don't feel comfortable sharing this. This needs to stay here with you guys. I have autism. And they are going to be wow! No way! I had no idea. That is empowering for both parties. And on the broader picture for the disability movement we need allies, and people need to get on board for making cultural change. Denying some of those opportunities could be personally harmful and harmful for the greater system.

David and Richard explained that nondisclosure is a theme shared by many college students with ASD.

When asked why he did not disclose his autism to peers, Nathan responded, I don't share with my peers that I have a disability, because I don't want people to see me as this thing, rather than who I am. I don't want to feel like less of a person because of it. I don't want other people to make me feel like less of a person or different because of it. I want people to treat me the way they would

treat any other person, with respect and without pity. Not, oh you poor thing you weren't born with common sense of social interactions; oh man, here let me go out with you so that you feel better. I don't want people to pity me at all. I want them to just look at me as any person.... I try very hard to act normal. In the process of trying to act normal, I have a mask on trying to be like someone else, pretending.

Nathan explained that:

I have trained myself to be able to overcome the things an autistic kid would have problems with: like eye contact, being able to talk, have conversations. So it's kind of like hiding in a way; forcing myself to do things that scare me or make me feel insecure. It becomes overwhelming...it takes energy.

Nathan explained how he worked on developing these skills. "So, I started looking at movies—what do I do different than them? I would notice when I walked I don't move my hands back and forth like they do." Nathan practiced typical body movements until they became automatic. As Nathan got older he continued to develop social skills that were not inherent to him through taking acting classes. The acting classes taught him how to read emotions better through developing an understanding of the characters.

Nathan shared there are no exceptions to his nondisclosure with peers, even romantic partners. Nathan used dating as an example to convey the challenges, and discrimination he has of having ASD, and being black. He states that the prior relates to him, his need to develop awareness, the social skill. And the latter is due to social barriers. "So I have both problems. Once I overcome the socializing, can you overcome

my skin color and I have a lot of unsuccessful attempts socializing.” Sandy provided her understanding of Nathan’s feeling of dual discrimination.

The dating thing bothers him. He is bothered that he is biracial. He is bothered about being different as far as the autism. And that he doesn’t seem to know how to connect with people, like you know, a dating relationship....telling me when he talks to girls, they consider him black, or their parents would consider him black. They can’t date him. So he hasn’t found anyone that like he fits in. He doesn’t connect with a lot of African Americans because his culture was more in a white area culture-wise. So I see how he is disconnected to a lot of people. I don’t think that this is a terrible area, or that we have huge racism going on, but I do feel he feels disconnected and that he feels the dating pool is very limited. That’s one of the fears he has on top of someone finding out about his autism. That’s gonna put another mark on him.

While Nathan reports that there are no exceptions with disclosure to peers, there is one exception to Nathan’s nondisclosure. Nathan is very focused on his academic success. He states, “I don’t want to just be an engineer, I want to be one of the best engineers.” To achieve this end, and get the support that would allow him to do his best, he had to go through the formal process of disclosing his disability to Disability Services at NCU. To receive accommodations under 504 of the Rehabilitation Act and ADA, it is the student’s responsibility to request accommodations, and provide verification of the disability from a qualified professional. Nathan with his mother’s assistance took the needed steps to apply for accommodations prior to the start of school.

David expressed that the Disability Services office was the one safe place for Nathan to open-up about his disability.

Because we represent disability, and we have that rapport with him, what tends to come out in sessions here are things related to his disability. This is the safe place he can do that. He doesn't do that anywhere else on campus. This is where he lets his guard down. We can see it; he can be with the same people over the social group where he lets his guard down and he talks about all of this. You put him with the same people outside of that room, it's gone! He has the guard right back up. When he is here that is what comes out the most, because this is where he can process disability.

In regard to accessing support from the Disability Services Nathan stated "I mean without the support system I don't think I can function as well as I want to. I might become a B student. That sucks for me. That's like an F." He stated, "Initially I didn't really like getting support, but I know without them I can't do it." Nathan does not have any concerns about disclosing to his professors that he has a disability and he stated, "I talk to them in the office hours, every single one of them... they understand because they have worked to be teachers for one, so they have experience teaching kids who are different than other kids." To exemplify the type of support most professors provide, Nathan described a situation he observed with another student with a disability:

He was freaking out because he couldn't take a test on time. He thought he was going to take the test. And he was oh, I am going to fail, oh my gosh, oh my gosh and no one could calm him down. So, they called the professor. The professor

went out of the class—stopped teaching the class—came all the way over to the disability center to calm the kid down, to tell him everything is going to be ok.

While Nathan needs, and is willing to use the support, it comes with the risk, the stress of is disability being disclosed. This is exemplified in his discussion of using a note taker.

I have gotten some really good notes from note takers. Sometimes my notes are as good as theirs, but it is nice to have them in case I missed something. So it's good. I just feel nervous asking because; oh, someone in the class needs notes. Makes me feel kind of nervous.

Nathan also chose to disclose his disability in one other situation, this study. He did so with caution. David shared that Nathan came to him after first meeting to discuss the study, David said, "He just needed to know that working with you was going to be safe.". Once assured that that it was safe to interact with this researcher, and the intent of the study was to help others. David shared, "He is letting you into his little secret world."

Proactive early nonacademic support is imperative. Nathan, David, Richard, and Sandy, each acknowledged that without the early extensive nonacademic support Nathan received, he would not have gotten where he was academically, or in his ability to manage his day-to-day life while at NCU. This support was imperative to his success. David and Richard discussed that this is not uncommon and is why they have developed a system for identifying student needs early on and providing nonacademic support.

NCU Disability Services, David and Richard, recognize the need to begin support service for students with ASD as soon as possible, often even before the student begins attending NCU. Supporting students with ASD is a twofold approach, academic

accommodations and nonacademic support. It is the latter that NCU provides the most intense focus on for students with ASD. David explained very passionately,

We spend a lot more time on nonacademic issues, where a lot of the other groups it is primarily academics....I found working with students on the spectrum it's almost never an academic issue, but on the surface it appears an academic issue....It's usually a nonacademic issue that can ruin academics. And so if we were only in the business of making sure they had accommodations in their classes, we would miss the real underlying things that are making the grades slip.

NCU Disability Services values early contact with students who have ASD and their family. They are proactive in initiating this interaction. David stated,

The foundation for providing services is establishing rapport. From the beginning what we try to create is a supportive welcoming relationship with the student and the family, to help ease the transition. We encourage them to come in the summer before they start and we meet with them in person to start creating the sense that we are the support team here at college.

This early contact begins the interaction process with the student. Richard explained, "The sooner we start having the opportunity to interact with the student, the more connected and comfortable they will be with coming to us for assistance." While the goal is to have the students be able to come to NCU Disability Services for support and guidance, it is a process to transition the student from their existing support system to the supports at NCU Disability Services. The Family is an important part of this transition. Richard stated, "I think most parents don't really realize how important transition planning is....The sooner they make contact with us, the sooner we can start having the

opportunity to interact with the student.” David explains the value of early family communication:

Often times the family can provide more insight than we are able to get just from interviews with the student, at the beginning. So family involvement is critical at the beginning to get a better understanding of what are the specific needs of the student. On a case-by-case basis we try to evaluate what is going to help this individual student succeed.... We usually start by asking what does the current support structure look like and figure out how we can begin to replicate that, if at all possible.

For Nathan, early family contact was certainly critical. Nathan’s mother began working with David about 6 weeks prior to the start of school. She had many concerns about the transition to college and communicated often. She inquired about what services were available and what support could be provided. David recalled,

She was looking for a source that she could rely on for some of the problem solving and a place where she could help encourage Nathan to go when he was having challenges and have that trust and faith in the place as opposed to just sending him somewhere that would not get support and kind of backfire, because she knew that wouldn’t work.

Richard added, “I think mom needed to find a resource or a connection to replace her or she wouldn’t feel comfortable with fully stepping out of the equation so he could fully experience college as a college student.”

Much was learned through this early communication with Sandy and Nathan. David and Richard learned that Sandy was Nathan’s primary support. She understood

him and would process things for him to understand and be able to function. Thus, the transition of support would be from mom to NCU Disability Services. Through information gathered from mom, intake information completed by Nathan, and documentation relating to his diagnosis and accommodation needs, David explained, it became evident that,

It was a delicate hand off and I would say mom was probably very anxious and was going to have a difficult time letting go and passing the torch on to the institution in some ways. Because I think she had a very hands-on day-to-day fully involved approach in providing support.

Though early contact with Mom and Nathan, David and Richard determined the support services they would offer Nathan. They felt he would benefit from participating in the full offerings they had for students with ASD—Social support group, coaching, working with counseling center and academic accommodations. Nathan would be among the first cohort to have services include a social skills support group. They planned to begin meeting with him during orientation prior to classes starting.

This early communication led to the arrangement for Nathan to have a single dorm room, which was very important to Nathan's success in living on campus, and in turn his academic success. In arranging this physical support, single room, and the visit to see it during the summer, Disability Services Office had to educate, and gain the support of housing, to arrange the room, and, more out of the ordinary, the visit to his particular room.

Nathan reflected on his early contact with NCU Disability Services. He recalled, "My mom made sure I knew where to go and who to talk to if I had problems."

However, initially he did not feel comfortable going directly to David or Richard so he explained, “ My mom would communicate with them when I had a problem and I wouldn’t go to them.” Nathan did not like communicating through his mother. David stated,

But it worked.... I still don’t think he liked it. Because it goes back to the, oh I got autism I have to have my mom to call and.... But at the same point he didn’t have the comfort level to communicate.... He felt comfortable sharing it with mom. So we really worked with him around being more comfortable asking us for help and that started to happen.

Upon arriving on campus Nathan began receiving nonacademic support immediately. Richard was the primary support provider through Disability Services. He had regular weekly scheduled appointments to develop a rapport with him and for coaching. This is a proactive step NCU Disability services takes for students with autism. David and Richard explained they schedule weekly coaching appointments for students transitioning. It is a standing schedule. David stated this is because “the first time away from home is nothing to be taken lightly. The anxiety just skyrockets with this population,” David said. “There are so many new things they must figure out.”

The product of Nathan receiving comprehensive nonacademic support was Nathan gradually increased his ability to communicate directly with NCU Disability Services, transferring some support from mom to NCU during his first year. He was also able to remain on campus, and excelled academically.

Throughout this process of transitioning support from mom to NCU, Sandy maintained close communication with David and Richard. There was open communication, however, David shared,

Mom probably thinks she was a burden to us in some way. Because she was always apologizing and for just showing up in the office.... She wasn't a burden. And what they don't realize is I appreciate that because I don't know these students quite as well as family does. And it's part of that transition. we need family if we want to have a successful hand off.

This process is very time intensive at the beginning, David and Richard reported. David stated, "I'm so willing to invest all the time at the beginning, because once you get the structure in place they roll with it. Richard, shared:

What I have noticed, once you build credibility with the students with autism, so they understand, hey this person knows what they are talking about. And they have some sort of guiding light then they are more apt to, in our coaching, to be receptive to what we find together and to follow through on it

David and Richard shared that Nathan is not alone in his success. For students who fully participate, were invested in the process of coaching and social group not only achieved higher grades, but the retention rate was 100%. David stated,

When we started the social group, we retained every single one of them who participated in the group. And we lost 25% of those who did not participate. We were looking at grades.... we did an assessment on this. We looked at the grades of those that participated and those who didn't and it was 3. something vs a 1. something. And so that was wow. This is fascinating, amazing, and our

assessment guru ”is this accurate and you retained every single one of them”... I don’t even look at retention. Yah, she’s like “and the nonparticipants you lost 25%. They dropped out or disqualified or something” she is like ”the real story is not the GPA. It’s retention.”

Another factor that David and Richard discussed is that the students who followed through on participating in the support were student’s whose family encouraged and expected them to utilize the nonacademic supports. David stated,

“We see a difference between when their parents or whoever is on their team prior to them getting here lets them know the importance of participating in the coaching. And that it is expected of them when they get here. As opposed to it is not already coming from people that they trust who are invested in them whether or not they actually participate in the coaching and receive the benefit of it.”

Coaching from freak-out to function. Coaching an intervention used by NCU Disability Services that all participants discussed was highly beneficial for Nathan. It helped Nathan get through situations in which he was “freaking-out” and in developing his ability to independently think through challenging situations. Through this process Nathan went from freaking-out, or a state of being paralyzed by overwhelming feelings of not knowing what to do, as a freshmen, to being able to recognize he is having a challenge, and either handling it on his own or, if needed, seeking out support from Disability Services or other sources.

Coaching is a method of guiding students rather than telling them what to do. David explained why he moved to using coaching, “You can’t just give advice and tell students what to do, because nobody does it! Coaching allows the student to come to a

conclusion on his or her own, on an action item they're going to take.'" He explains the process of coaching as follows:

We use the "Life Bound Model." Basically, it is academic coaching, but it does cover some different spectrums. What we do is create a safe environment where you explore a concept with a student by asking questions, only questions. To help them explore it in a safe way, because often times they haven't thought through some of these things. We get them thinking about it. The goal is to come up with an action item that the student initiates, states and says he or she would be willing to do it. Then the next time we start off by asking them questions about that action item. Did they follow-up on it? How did it change?

For students with autism, David and Richard explained they schedule weekly coaching appointments for students transitioning. It is a standing schedule. They do this because as David stated, "The first time away from home is nothing to be taken lightly. The anxiety just skyrockets with this population. There are so many new things they must figure out."

Nathan had weekly coaching appointments with Richard, and if issues arose in between sessions, Richard and David were available as well. Nathan's mother encouraged him, to meet with Richard, and continues to direct Nathan to seek his assistance for school related issues. Sandy expressed:

It was imperative at the beginning. That has been such a key element to making this work that the Disabilities Department having a grad student to kind of shadow these kids, if they need it. Have them meet once a week if they need it, or as often as the need. I don't think Nathan meets with them once a week any

more. Sometimes, even now, if Nathan has a problem, I tell him I have no idea how a college handles it. Call up Richard and ask him for help.

Richard provided a majority of the coaching for Nathan, and, too, saw his progressive independent use of these skills. He reflected,

I would say that is evident in the fact that any time, initially Nathan's first two semesters we would here if there was something going on from his mom first.

And then basically he started to change gradually coming to us to ask for guidance and or coaching. Then that also gradually change to him coming this happened and this is what I did.

David added, "Now he is able to ask himself the questions. He is finding solutions on his own. He now says, 'Here is what happened. Here is what I did and here is my strategy.'"

David went on to explain, "Recently he came up with a solution that I would have never proposed. It worked for him. It was in regards to a problem with his fraternity." He found a different advocate and resolved the whole situation on his own. And he had support.

It was evident during Nathan's interviews that he saw value in, and embraced the process. Nathan discussed many areas that Richard had helped him through coaching. These included scheduling his time, working out class schedules, and many different issues regarding dating and social interactions. As David noted he has come full circle. He is now able to independently use the strategies. What truly exemplified that he has come full-circle was when he was able to recognize that another student with a disability for whom he was tutoring, needed coaching. He stated,

I am not like qualified to tell him what to do. Richard knows how to tell them...

What he does is makes suggestions and then he looks at their suggestions, and makes them see all the negative consequences of their discussions, and then eventually they lead themselves to the answers that he wanted them to look at.

That is his process. He has been doing with me. He helps me see all the negative consequences of what I do and then seeing what if you did this look this negative consequences compared to the positive. Oh, wow you're right! I should do this.

Instead of telling me I should just do it. Richard, when I felt really depressed, used this to even make the suggestion 'you should consider counseling.'

Support from Mom—invisible, but essential. Sandy, mom, provided essential support for Nathan to be able to integrate into, and be successful, at NCU. Sandy's support started long before Nathan went to college, and once at NCU it took a different form than parental support of neurotypical peers. Nathan, David, Richard and Sandy presented evidence of the essential nature of Sandy's support as a component of Nathan's success, each from their differing vantage points. Consistent across all respondents was that Nathan did not want his mom seen on campus helping him due to his fear of the social stigma, thus, support needed to be invisible to his peers.

Sandy, throughout Nathan's life has been instrumental in facilitating Nathan's ability to succeed academically, and in helping develop skills toward independence. As he was growing up Sandy developed a deep understanding of Nathans needs, and how he integrated with his environment. For example, Sandy explained when discussing Nathan as a young child. "He would get frustrated if things weren't organized. He wouldn't necessarily be able to organize them himself. But he wanted them organized." She

would help him keep things in an organized manner that was comfortable for him.

Having this deep understanding of his needs allows her to predict areas that he continues to require support, and help encourage, and develop self-reliance. In some areas he still requires support such as with organization, as it remains an area of skill deficit for Nathan. Sandy explained,

The more organized it is, the easier it is for him. I think that has been a big problem is his organization. He doesn't have the skills. Richard helped him, and he seems...um... much more at ease if he feels like everything is organized, and he has a routine.

Sandy gave the following example of how, in regard to his organization, she continues to support him.

Nathan needs a lot of help transitioning, getting into the little dorm and when it is time to leave. The move is a big deal. That's not something that just kind of happens with Nathan—packing stuff up—so, not the typical college student where they are going to move themselves to and from. I try to initiate him being more independent that way I'll drop off the boxes, I'll remind him a couple weeks ahead or even during the week. Honest truth is I will come two days before, and I'll show up, and he says he has packed and he hasn't packed. I don't know how to explain it. So I just come prepared that we're going to have to pack up.

Sandy supported Nathan as he has attended NCU at the beginning, freshman year, by educating Richard about Nathan's needs and functioned as a liaison between Nathan, and disability services. This resulted in Richard and David being able to provide the needed support relating to college issues. She stated,

They picked up on the side that I am not involved in and that I don't want to have to be involved in. I want him to feel independent.... They helped Nathan be independent. And I think it's been a learning experience. You just have to wait and see what does a student need. Richard has picked up on that.

David and Richard valued the early communication from Sandy, which led to them being able to support him, and transition him to rely on them to assist him with his needs for support relating to all aspects of his college experience. They felt that mom felt like a bother at first, but that was not their impression. David stated,

I think that mom was— people might have used terms like helicopter parent or too protective. I think mom was very helpful for him in a lot of ways. She understood exactly what she was doing, and knew at some point that there would have to be this trade off. And I think he understood it as well. I think there was some good upbringing and teaching on her part with preparing him for this.

Richard added, "It seemed like she kept him in the loop of learning about his disability, his diagnosis. Whereas some parents don't fully disclose or fully understand."

Sandy's deep understanding of Nathan's needs, and responses to environmental factors, led to another essential support during his freshman year. She understood his fear of germs. Based on this knowledge, she was able to create a system that would work for Nathan to shower in the community bathrooms. Sandy explained,

He voiced his opinion about things he thought he couldn't get past, or live with.

And then I tried to come up with ideas of how we can get around this to the point where he is as comfortable as possible.

Sandy came up with a system that would keep everything from touching the bathroom surfaces using hooks, and sewing loops on everything. This was completely customized to the environment, and Nathan's specific needs.

Sandy also continues to provide emotional support. She stated, "I am the person he calls at like 5:00 a.m." with a laugh. Nathan concurred with this stating,

Maybe I won't be able to see Richard the same day, or maybe it's the middle of the night, and I am freaking out with no one to talk to. So I talk to my mom and it actually makes me feel a lot better.

Sandy provides support relating to medical issues. One issue is, Nathan doesn't realize when he is sick. Sandy explained,

Nathan has an extremely high tolerance, threshold of pain, and so by the time he goes for help, it's almost like emergency room status.... Gotten the call at 3:00 in the morning. Mom I am really sick. I think I need to go the doctor. Well he probably should have gone to the doctor 3 days before because now he needs to get to an emergency room.

Sandy has been working with Nathan to take notice of his symptoms sooner.

The second area of medical related support Sandy provides is going to doctor appointments. Sandy expressed that she does not want to have to go to appointments. She wants Nathan to go by himself, but he does not communicate to the doctor what is wrong, or feel comfortable going by himself. He wants Sandy to go with him. Sandy gave the following example,

I go to the rheumatologist with him and he has made the appointment because his back is hurting so bad he can't sleep. And he'll ask him why he is

there and he is like oh yah just a follow up and I am just waiting letting him do all the talking. The doctor turns around and gives me that eye what's wrong. He is asking him questions, and not coming out with what is wrong. So, I either say Nathan do you remember when you called me you couldn't lean forward, couldn't sit in the chair. Oh yah, I am having this horrible pain right here. ... The Rheumatologist knows Nathan's issues. He lets Nathan talk and then he turns around and gives me the eye. Ok, mom what is it exactly.

Sandy also provides support by running small errands and doing chores. Nathan may call Sandy to have her pick something up for him if he is overwhelmed, or if she is at Nathan's apartment and notices something needs to be done, such as a load of laundry (takes with her), or garbage needs to be taken out. Nathan on one hand finds it favorable to have his mom close enough that if he needs help getting something or doing something, but on the other hand does not want her to be seen on campus helping him for fear of peers seeing her there, due to his perception of the stigma of a male student needing help from his mother. He stated,

In America having your mom help you is a weakness because of gender stereotype roles. Because, if you were a female it wouldn't be a problem. Ah her mom is here, and she is spending time with her. Because I am a man, a male, they see that as oh, he is a mama's boy. Ohooo, he is not a man, not independent. So if they see my mom on campus they will think, oh, wow. What a dork.

In addition to emotional support from his mom, Nathan talked about how he can always get advice on what to do. This may be in everyday situations such as how to

wash clothes, setting up doctors' appointments, financial matters, when he is having social challenges, or in somewhat a more urgent situation to help him problem-solve about what to do. Nathan shared the following situation that was urgent and he did not know how to proceed.

I cut my hand. What do I do? You need to go to the emergency room. Where is that? How am I going to drive if my finger is cut? I can't drive. Well, call the campus and I call the campus. Well can't you get a friend to drive you. My hand is bleeding. I don't have anyone else. Why don't you drive there? Oh yah that's a good idea. I will just drive with my open wound. Ok, fine. We will send a cop to go get you over there.

Nathan has a positive relationship with his mom, when she is in town they will do things together off campus. He stated in regards to Sandy's support,

She is always advocating for me.... She even setup a court case and like tried to like go against the whole school board to advocate for me. She has always been there defending me, helping me out, and being able to try to learn and get help for my problem. She has probably been the most understanding person for my problem. I don't think anyone understands my problem more then she does.

Individualized approach by dedicated professionals. David and Richard at NCU are synonymous with NCU disability services. Through David and Richard's description of how they provide support and their service philosophy, along with accounts of support they, Nathan and Sandy provided revealed that they have an unwavering dedication to student success. To assist students, they use a highly individualized approach, or as David refers to it as an "individual catered approach."

They are not merely concerned with meeting the legal mandate to accommodate, but are concerned with the wellbeing of the whole student, and focus on each student's individual needs. Richard summed up their approach as follows,

It is our commitment to students and their wellbeing first. Even before academic success. I think they are able to pick up on that, not to toot our own horns, but I think it just actually comes through. I had a professor tell me students will never care how much you know until they know how much you care.

For students with ASD David and Richard take a proactive hands-on approach. That is frequent face-to-face contact through coaching, social support group, and working through individual student challenges, and celebrating successes. Due to the nature of ASD, as was the case with Nathan, students do not readily seek out assistance. Having this understanding along with knowing potential challenges that may occur for students with ASD in a new environment, David and Richard reach out to them.

Richard's initial face-to-face contact with Nathan exemplifies this approach. Nathan was attending a dinner for students and their parents and a special orientation event that started a couple of days prior to the general orientation. Richard was a part of the group putting on the event, as part of his master's program. He recognized Nathan's name as an incoming freshman that he would be providing support to as part of his work with Disability Services. Nathan appeared quite stressed. Richard introduced himself and explained his role with Disability Services. He took Nathan and his mom aside and he gave them strategies of how to get through the event. Richard provided Nathan his phone number and let him know that he was staying on campus that night, so if he needed

any assistance he could call, and he would come over. Richard felt that this put Sandy at ease, since this was not only Nathan's first night at NCU, but also his first night away from home without his family. Richard shared with a sense of accomplishment how this fits in with their, NCU, approach

I could have remained anonymous. I could have seen what was going on and just acted as though I didn't understand it or didn't see it, but I think that the active part of reaching out, hey I already know who you are and I already know that we are working with you and I want to introduce myself and I want to let you know I am here to support you. I think that is what possibly created the level of comfort for both the student and his mom.... That's the impression I got. It went from major freak-out to, he's staying,

For David and Richard reaching out, at times, goes beyond looking at what an individual student needs, to how to improve services for a group of students, or educating and supporting the campus community. An example of the prior is the development of the social support group. David explained,

We were not asked to put a social group together as a collaborative partnership with counseling services.... We volunteered at first, all of us. We did it after hours. And now, especially on the side from the counseling center, it has received enough buy in that.... It is now part of their structured responsibilities.

David and Richard shared a situation where their reaching out was not direct support for a student with ASD, but the class as a whole. David stated,

We had a student with autism who we knew was going into a very, very difficult economics course and the professor was freaking out because in the lower level

course before, this person was basically in need of multiple hours a week of additional explanation from the faculty member and which was never going to work in this class. The way the class was set up is that they only have a little bit of lecture time and then the majority of class is done workshop style. Where they are interacting, engaging the material and raising their hand to talk to the professor when they had a question. So we knew this student was gonna have their hand up the entire time. So, behind the scenes, I worked with the faculty member. And we hired basically a supplemental instructor.... a student who had already taken the class to walk around with the professor and answer questions.... This wasn't just for that student. So anybody could take advantage of it. But, we did it because of the student with autism. Nobody would know that, especially the student with autism.

Nathan's account of the support he received from NCU Disability services, or David and Richard, conveyed that they are very dedicated to all the students they served. He shared not only about the intense support they provided him, but also scenarios about support he observed them providing to other students. He stated,

It's because they care and you can tell they actually care. They are not doing this for a paycheck, and they go beyond their duty they go beyond what is required of them every single day. David made a list on his app they helped this kid graduate.... he would monitor to see if the kid posted on the list and if he didn't post, he would email him like, hey you didn't update your list... to the point where he was able to graduate.... It's not part of his job description, No but he did it anyway because he cares. That's what Richard would do, too. If a

student needed extra help even if it was like in the middle of the weekend or something and you call Richard, he'll be there to talk to you. He will be there to help you out. If you are stressed out or something, he is there... They don't just care about what they are hired to do. They're there because they love helping people who need help and you can see that and it shows.

In addition to going above and beyond, Nathan also described David and Richard as having a deep understanding of the needs of students. This is exemplified in regard to Nathan having a fear of germs and needing to adjust to using shared bathrooms in the dorm. Nathan explained,

David and Richard helped me. I didn't have to go to the bathroom over there I felt like I couldn't I could go to their office and use the bathroom. They showed me all the bathrooms I could use—in the library, all these places.... That was a big help!

As he continued reflecting on David and Richard support, Nathan explained that they are well-liked. Professors have expressed that they like having an excuse to go see them when Nathan has given them papers. He stated,

Everyone really likes them, I think most of the professors like are really open in communicating with them because they enjoy talking with them and then they understand what they represent and they love like how they are dedicated to helping kids and stuff. So, because we're a small school and there are not a whole bunch of them, it's just.... these two people. It seems like they are at the top of the hierarchy here. They're like basically carrying the whole team of students with disabilities on their backs and helping keep the thing alive. I mean, without David

and Richard, I don't think there would be Disabilities Services that would be quite as good, or efficient.

"I really do appreciate the NCU disabilities department. It has been outstanding.... I have been really pleased with the support from the disabilities office at NCU. I think it is a big part of his success and ability to live on campus," Sandy stated when reflecting on Nathan's support. She had discussed that without the support that Nathan received, he would have had to live at home and commute. Which, both Sandy and Nathan expressed, would have been too difficult for Nathan to manage. Sandy felt that Richard being on call for Nathan was one of the critical factors that assisted Nathan in being able to get through difficult times. She explained, they:

Guided Nathan with what needs to be done, when there is a problem, because he doesn't always know what to do if there is an issue. He has gotten better with their guidance. He is advocating for himself. I think it is just the comfort part.... he knows he has somebody to fall back on and call if there is a crisis. He is right there on campus.

Textures of Nathan's Autism. How Nathan experiences his environment, that is, how he takes in information and physical sensations relating to his ASD were conveyed through all respondents' descriptions of Nathan's predicament of autism while attending NCU. These textures of his ASD were also shared through precollege experiences Nathan and Sandy discussed.

One aspect of Nathan's experience of ASD that was conveyed by Nathan, David, Richard and Sandy was Nathan's thinking in comparisons, or to some extent what could be described as black and white thinking. This process guides his actions, and when

there is nothing to compare with he finds it difficult to proceed. This occurred when faced with new situations at NCU. Among the new situations were needing to schedule his classes for the second semester, dealing with illness/injury's away from home, new living arrangements, and social encounters.

Nathan compares himself to what he perceives as those who are “normal” resulting in his needing to “fix himself” to be like “the next guy” and have the same life opportunities. He explained that this process began when he was at the end of fourth grade, when he realized that his lack of social interaction was not normal. He felt sad that he did not have the same social opportunities as others his age. He stated, “I don't want to feel different. I want to have the same interactions the next guy has.” Nathan explained when he made this decision, he began this process, “I look at myself and compare myself to others and thinking how am I different?” He explained that when he was a “kid”:

I always kind of looked at myself in the third person. If I was a character in one of the books I read, or the movies I watch, how would I perceive that character. How can I make myself look better? When I was in elementary school, I was so socially awkward—why do people see me as weird? So I was always looking at the movies—what do I do different than them? And then I notice when I walk I don't move my hands back and forth like they do. Like that makes me look weird.... These body movements will help me look better. Then it just became automatic... I guess just knowing, like figuring out at first that I was different and then trying to look at myself and compare myself to others and thinking how am I

different? So, I tried to look at myself, always judging my own actions. Seeing if that is really how I want to represent myself.

Nathan continues to compare his behavior against others. David noted, “He is constantly benchmarking himself.”

When describing his social interaction at NCU Nathan used comparisons with both a typical student “the next guy,” and compared his progress with other “kids” with ASD. Nathan, in comparison to peers he would describe as normal, expressed that he does not like to participate in activities that are typical for college students such as parties or dances, he explained:

They are awkward. I know that there’s events on campus that people enjoy like going to the basketball games and like going to like I said dances, I don’t participate in the social events on campus that much just like the other guy, because I would rather be working on homework and stuff. But it makes me feel bad that I don’t interact with people. I don’t really see a lot of people.

While most of the comparisons he makes with his peers are perceived deficits, there is one area that, in comparison, he feels his ASD gives him an advantage over peers. He stated,

I am able to program things that people don’t think about. And it gives me more focus on my work because I want to focus on work all the time. Other people don’t have the endurance to focus on work all the time. Where I do. I have more endurance to work harder than other people to focus on things and learn more stuff, because, and you know look at any autistic person, if he likes something, he knows it inside and out.

Nathan's comparative thinking is also noted when Nathan conveyed that he likes rules. While at the time of this study he had come to resolve that some rules are not always followed, when he was little he could not stand it when other kids would not follow rules. He said, "I used to be really uptight and I would rat them out sometimes. It's not fair. Why should I follow the rules and you not?" Whether self-created or external, rules give Nathan a guide as to what to expect, and what to do. Nathan likes the external rules imposed by campus housing. He explained,

In junior year you don't live in the dorms. You can't. So they make you live in a campus apartment, or off campus. I live in the NCU houses, which are on campus. It's still funded by the school and stuff so if someone is loud I can still call. It's like living in a dorm but bigger and better.... We live by the dorm rules and everything is really nice.

Nathan also compares himself with other students with ASD at NCU with whom he attends social group. He sees himself, as having some of the same challenges as other students with ASD, yet perceives that he has progressed further. He explained that Social Group is:

This group is kind of like autistic anonymous or something. We all come in and are like hey my name is Bob. Hey, Bob and then we talk about our problems and stuff or just talk about whatever we like to talk about. It is really nice to see I am not the only one going through the same problem. There are other kids who go I don't know what to do when it comes to dating. And we talk about dating a lot because that is really hard for a male autistic kid to get his head around because there are so many things to think about and no rules. It's already hard to figure

out if you are a normal person. What the other person is thinking about but then you don't know what is common to think about with interactions. It makes it harder, a lot of ground to cover. And some of these kids haven't been trying as long as I have to figure it out.

Nathan reported that he valued being able to go to Richard to get help in developing an understanding of social relationships. Through these conversations with Richard, and Support Group, Nathan established his rule for dating: never kiss a girl without her consent.

Sandy concurred on Nathan's difficulty in developing relationships, including dating. She said:

He doesn't seem to know how to connect with people, like, you know, a dating relationship. He doesn't want to make a move that would be considered sexual harassment, so he doesn't want to kiss a girl first without asking. Everything is very black and white. There is no gray area with him.

Nathan has both heightened and repressed sensory experiences. He shared that when he was young, he was freaked out by loud noises, such as fire drills. He also has visual sensitivity to light, resulting in at times needing to wear sunglasses indoors. David explained that the florescent lighting in the room where Nathan tests makes it difficult for Nathan to work, so there is alternative lighting available.

Sandy shared that Nathan was sensitive to touch from an early age. He did not like being touched or hugged. David shared a discussion that Nathan was leading in Social Group regarding the physical sensations associated with ASD and touch. It provides a descriptive account of what Nathan, and since all group members concurred to

some extent, and others with ASD experience. David recounts with intensity, this discussion.

Anybody ever get that weird feeling if you like touch a girl? Like even if it is a handshake. They're like, yeah, I never can describe it, or if you got a hug, he said, it makes the top of your head feel weird, kind of goes all the way through your body. And they're all like, yeah, yeah. What is that? And he is like, it is so overwhelming, you can't do it

Nathan also described the physical and emotional feeling of socializing, on several occasions describing as a strained muscle when over-taxed from social interaction. He said:

It becomes overwhelming... it takes me energy to even be able to do these kind of things to have social interactions. That's why I can't keep on if I am tired then I won't do it at all when I am tired. Cause, I don't have enough energy. Some people it is effortless. Me, it takes a lot of effort and it shows the longer I stay in these social situations, the more tired I get. It is draining. I can feel it draining me. I am forcing myself to do something that is unnatural.

Summary

This chapter presented the findings of this study. Data analysis yielded a case profile, and six themes emerged through the process of coding. The case profile was created through interwoven data from Nathan, student, David and Richard Director and Assistant Director of Disabilities Services at (NCU) respectively, and Sandy, Nathan's mother. The case profile provides a deep, rich description of relevant contextual

information from Nathan's early years, educational experiences, and how Nathan was supported while attending NCU. The themes that emerged are: Ubiquity of disclosure, proactive early nonacademic support is imperative, coaching from freak-out to function, support from Mom, invisible, but essential, individualized approach by dedicated professionals, and textures of Nathan's autism. These themes provide insight into Nathan's support and his experience of support while attending NCU.

Chapter 5: Discussion, Conclusion and Recommendations

Introduction

The “autism tsunami” is upon us, and our nation is not prepared. There is an estimated 50,000 students who have Autism Spectrum Disorder (ASD) that are reaching adulthood, and exiting secondary education annually. Tsunami is used to describe this group because there are an overwhelming number of individuals hitting the adult service system with a wide range of needs for services and supports, with our nation unprepared for the wave. The National Autism Indicators Report, “Transition to Adulthood,” (Roux et al., 2015) stated there is a lack of services available to support young adults with ASD in being self-sustaining, contributing members of their communities. The report indicated that 37% of adults in their early 20s, who have ASD, have never worked or attended any postsecondary educational program. And due to the lack of appropriate accommodations in these programs, there is a low rate of completion for those who enroll. There are an increasing number of individuals who were identified early in their lives with ASD, and have received early interventions and support needed to exit secondary education with diplomas. These positive educational outcomes has resulted in a burgeoning number of individuals holding the diagnosis of ASD able to, and enrolling in postsecondary education at IHEs (Roux, et al., 2015; VanBergeijk, Klin & Volkmar, 2008). For these students, the predicament of attending an IHE may pose unique challenges in academics, social interactions, and the ability to perform daily living

activities. Despite an ever-increasing need to support individuals with ASD while they attend IHEs, there is only a scant amount of emerging literature on this topic (Gelbar, Smith & Reichow, 2014).

This exploratory case study was conducted to gain an in-depth understanding of the ways in which Nathan, a student with ASD, was supported while he attended North Coast University (NCU), with the intent to inform further research, and affect the practice of service providers who work with students with ASD while attending IHEs. The results of this study yielded an in-depth understanding of how NCU Disability Service providers, David and Richard, and his Mother, Sandy, supported Nathan as he attended NCU, and of Nathan's lived experience of support.

This, the final chapter of this dissertation, will present in the first section a discussion of study findings. This discussion will include a view of disability through the lens of the Interactional Model of Disability and responses to the questions that guided this study as they relate to Nathan's experience of Support while attending NCU. The second section, Conclusion, will present what has been discovered in this study. The third, and final section of this chapter, will present recommendations for practice and future research that have emerged from the findings in this study.

Discussion

This section will present discussion of the findings in this study relative to limited prior research and dominant writings on the topic. The findings in this study were presented in Chapter 4 as a case profile and six themes. The case profile was created through interwoven data from Nathan, student, David and Richard, Director and Assistant

Director of Disabilities Services at (NCU) respectively, and Sandy, Nathan's mother.

The case profile provides a deep rich description of relevant contextual information from Nathan's early years, educational experiences, and how Nathan was supported while attending NCU. The themes that emerged are: ubiquity of disclosure, proactive early nonacademic support is imperative, coaching from freak-out to function, support from Mom, invisible but essential, individualized approach by dedicated professionals, and textures of Nathan's autism. The discussion will begin with the Interactional Model of Disability, the theoretical lens used in this study, and followed by responses to the questions that guided this study.

ASD through the lens of the Interactional Model of Disability. The theoretical lens, Interactive Model of Disability, guided the understanding of the data in this study. Prior to gaining a deep understanding of Nathan's predicament of having ASD while attending NCU, there must be an understanding of the broader construct of disability. For, ASD is a subset of that construct.

There have been two constructs of disability that have dominated the landscape of disability theory and models. The earliest, known as the Medical Model, views disability as an individual burden and personal tragedy (Linton, 2010). The second, emerging from the civil rights movements of the 1960s, is the Social Model, which views disability as a result of disabling barriers (social, economic, cultural and political), and not the individual including their impairment (Barnes & Mercer, 2010). Neither of these models embodies the experience of impairment in the context of the individual's lived experience. The Interactional Model of Disability asserts that people are disabled by their bodies and by society and that impairment is present, and its effects are experienced

regardless of other intrinsic attributes of the individual and external influences.

(Shakespeare, 2014). This model explains that the experience of disability

Results from the relationship between factors intrinsic to the individual, and extrinsic factors arising from the wider context in which she finds herself.

Among the intrinsic factors are issues such as: the nature and severity of her impairment, her own attitudes to it, her personal qualities and abilities, and her personality. The contextual factors influence these intrinsic factors: impairment may be caused by poverty or war; personality may be influenced by upbringing and culture, etc. Among the contextual factors are: the attitudes and reactions of others, the extent to which the environment is enabling or disabling, and wider cultural, social and economic issues relevant to disability in that society (p. 75).

Thus, disability is derived through complex interplay between the individual with the impairment, and the individual, community, and society with whom they interact. When the impairment is ASD, this interaction becomes even more dynamic since the impairment rests in the way the individual interprets and interacts with the environment. ASD is defined as impairment in social, communication, criterion A, and repetitive, restrictive behavior, criterion B (APA, 2013).

An over-simplified way of viewing the Interactional Model of Disability is as three components: impairment and its effects, intrinsic factors of the impaired individual, and extrinsic factors which interact to construct the experience of disability. This also can only represent a static moment, and not the fluid situation that actually occurs.

When viewing the data from this study, disability is viewed as the interaction between Nathan and extrinsic factors of NCU and society in general. For Nathan,

impairment would include impairments—ASD, anxiety, visual processing disorder and Tourette’s, and among identified impairment effects include attributes discussed in the theme textures of Nathan’s ASD—comparative thinking, sensory issues, and difficulty with social interactions. Intrinsic factors for Nathan are, for example, prior experiences of discrimination, family dynamics, and extreme perseverance. Extrinsic factors include NCU’s highly supportive disability services, parent support, peer attitudes toward invisible disabilities, and society’s view including representation of ASD in the media. A sample of this oversimplified view is presented below (see Table 3 below).

Table 3. Static Over Simplified Interactional Model

Impairment and its Effects	Intrinsic factors	Extrinsic factors
ASD Anxiety Visual processing disorder Turrets Comparative thinking Sensory-oversensitivity Difficulty - social interactions	Past discrimination Family dynamics Personality Extreme perseverance	NCU Highly Supportive Parent support Peer attitudes toward ASD Society’s view of ASD

Study Questions.

Overarching Question: In what ways is a student with Autism Spectrum

Disorder supported while he attends a four-year institution of higher education?

Nathan arrived at NCU with many unknown challenges ahead of him due to his predicament of ASD and comorbid conditions of anxiety disorder, Tourette’s, and an auditory processing disorder. It is common for students with ASD to have one or more comorbid condition (APA, 2013). While uniquely presented in each individual, Nathan

had common social/communication and behavioral features of ASD. The unique experience of Nathan's ASD emerged in the theme Textures of Nathan's ASD. Nathan has worked very hard to overcome these challenges. He stated:

I may have to go a different route to achieve things, but I know I can do more things because I work a certain way to achieve those things, so you got to believe in yourself for one. You can't just give up if you have a disability. You have to know that you just see it as another obstacle that you will never truly get rid of—being disabled.

This statement echoes the concepts in the Interactive Model of Disability (Shakespeare, 2014).

In addition to challenges, Nathan also has incredible resilience and perseverance. It is these attributes coupled with the comprehensive support he received from NCU and his mom that enabled his success while at NCU.

Although Nathan has great reluctance to disclose his disability, as noted in the theme ubiquity of disclosure, he, with the support of his mother, Sandy, went through the formal process of disclosing his disability to NCU disability services in order to receive accommodations. Unbeknownst to Nathan prior to starting at NCU, there were comprehensive services available to students with ASD. In recognition of the unique needs of students with ASD, NCU offers a comprehensive approach to nonacademic support. It is a highly individualized approach, and includes: early, and as needed, ongoing communication with family, one-on-one coaching, social group, counseling (through health services), environmental support, educating and supporting the campus community regarding characteristics of ASD and about support for the student. These

supports are provided at no additional cost to the students. This approach is in alignment with authors such as Barnhill (2014), Glennon (2001), and Wolf, Thierfeld Brown, and Bork (2009), who assert that nonacademic support is essential for a positive outcome for students with ASD.

Highly dedicated professionals, David, Director of Disability Services at NCU and Richard, Assistant Director, provided direct support for Nathan. David explained, “ We look at the student’s total needs for support. What do we need to help them with to grow and develop, to be more successful, and independent across the board.” Richard added, “We are committed to the overall wellbeing of the student.” They use a highly individualized approach that focuses on what each student needs to grow and develop to be more successful and independent. This emerged as the theme—the individualized approach by dedicated professionals. Thus, Nathan was afforded highly individualized support through Disability services. The details of this support are presented in the response to sub-question 1 below.

His mother, Sandy, also supported Nathan. Throughout Nathan’s life Sandy has been instrumental in facilitating his ability to succeed academically, and in helping develop skills toward independence. She has a deep understanding of Nathan’s needs, and how he integrates with his environment. Nathan expressed that his Mother understands his disability more than anyone. Sandy provided nonacademic support. Details are presented below in the response to sub-question 2. Her support was essential to Nathan’s success at NCU. This is described in the theme, support from Mom—invisible, but essential.

Sandy is not unique in her role in supporting a college student with ASD. The literature indicates that parents often provided support that made it possible for students to succeed, and the support was welcome by both the student and Disability Services professionals (Barnhill, 2014; Crawford, 2010; Mitchell & Beresford, 2014; Schlabach, 2008) Sandy provided support to Nathan in the areas reported as typical in the literature and include: coordinator/advocate, emotional supporter, social interpreter, and daily living activities supporter (Barnhill; Mitchell & Beresford, 2014; Schlabach, 2008; Shmulsky, Gobbo & Donahue, 2015).

Sandy sums up the importance of Nathan's support as follows:

I don't know if he would have been able to continue without the support of the school and the support of me. I really feel like he wouldn't. He would have had to go back and forth from home to school, which would have been very difficult. Honestly, I don't know if he would have been where he is right now without the support. I can see it could have turned completely in a different direction without support because of how overwhelmed he does get. I know about autism itself and what has happened in the past with him when he was at a much younger age—complete shutdown, giving up and shutdown....The possibility is there if he doesn't have the support he needs. It can go the opposite direction.

Sub-question 1. In what ways is a student with Autism Spectrum Disorder supported by a four-year institution of higher education he is attending?

NCU Disability Services, in addition to providing academic accommodations, has specific support services for students with ASD. In accordance with the American's with Disabilities Act and the Americans with Disabilities Act Amendment Act (ADAAA)

Nathan needed to initiate the request for these services through the process of self-disclosure of his disability. Once Nathan, with support from his mother, took the steps needed to qualify to receive accommodations, he received comprehensive support in meeting his needs associated with his ASD. Extremely dedicated professionals that were vested in his success provided the support.

NCU Disability Services holds a broad interpretation of the provisions of the legal mandate to accommodate in regard to ASD. There is great variance in the interpretation of what “reasonable accommodation” mandated by ADA and ADAAA, means in regard to students with ASD. While IHEs are mandated to provide “reasonable accommodations” in order to provide equal access to education without altering the essential elements of the academic programs, the type and extent of accommodations are not defined. In regard to serving students with ASD, some institutions interpret “reasonable accommodations” as needing to only provide accommodations in the area of academics, since that is the chief mission of the IHE (Glennon, 2001; Smith 2007; VanBergeijk, Klin & Volkmar, 2008). While others hold a more holistic and comprehensive perspective and assert that “reasonable accommodations” should apply to all aspects of the college experience (Glennon, 2001; VanBergeijk, Klin & Volkmar, 2008). Based on this study’s findings, NCU perspective is in alignment with the broader perspective presented by Glennon (2001) that states,

The mission of any college or university, however, is not simply academic advancement. The overall goals of any university experience include developing skills for adulthood, forming life-long relationships, identifying a vocational pathway, and/or participating in extracurricular activities. If ADA states that

individuals with a disability cannot be excluded from participation in services, activities, or programs of a public entity, then all of these activities would need to be supported (p. 185).

Brown (2017) identifies three ways that IHEs provide support directly to students with ASD—academic accommodations, general support, and ASD specific support. Nathan was supported in all three ways. Discussion will begin with ASD specific support, for without this, the academic and general support would not have been sufficient to afford him the same level of success.

ASD-specific support/service. “ASD-specific service refers to any service specifically designed to support students by targeting the functional limitations associated with ASD (Brown, 2017, p. 145).” NCU places an enormous amount of focus on nonacademic support relating to features of ASD. David and Richard assert that nonacademic issues can sabotage academic success, despite a student’s ability to complete the academic curriculum. They view nonacademic support as the key to student successfully meeting the academic and social demands of the college environment. This is a perspective shared by Adreon and Durocher (2007), Dillon (2007), Schlaback (2008) VanBergeijk, Klin and Volkmar (2008), and Wolf, Thierfeld Brown and Bork (2009). These authors also note that there is variance in how ASD impacts each student’s ability to successfully manage college life, as well as the amount and type of support needed. David and Richard’s practice is in alignment; they use a highly individualized approach. David explained that the approach they use “looks at the student’s total needs for support; what do we need to help them with to grow and develop to be more successful and independent across the board.”

Determining what specific support Nathan would need began during the summer prior to Nathan's arrival on campus for the fall semester. VanBergeijk, Klin and Volkmar (2008) advocate for support to begin prior to students beginning their academic programs. While Nathan completed a survey, which gave David and Richard insight to his needs, a majority of the planning was through numerous interactions with Nathan's mother, Sandy. The literature on IHE support for students with ASD indicates that it is common for the IHE to communicate with families, particularly early on. David concurred with Wolf, Thierfeld Brown and Bork (2009) when he stated,

Often times the family can provide more insight than we are able to get just from interviews with the student at the beginning. So, family involvement is critical at the beginning to get a better understanding of what are the specific needs of the student.

The early communication with Sandy allowed David to establish a plan for supporting Nathan upon his arrival at NCU. It also allowed for Nathan to have the physical accommodation of a single room. Communication with Sandy was ongoing and most intense in Nathan's first semester. As Nathan gradually became more comfortable seeking out assistance from David and Richard, a gradual shift from Nathan calling Sandy with concerns, to seeking out help from David and Richard occurred.

One of the themes that emerged in the data analysis of this case was proactive early nonacademic support is imperative. What this theme revealed is the intense early nonacademic support Nathan received was the cornerstone of his success. Knowing the potential challenges students with ASD face during their freshman year, David and

Richard are proactive in their provision of services. These challenges relate to both the social communication and behavioral features of ASD.

Nathan began receiving ASD specific nonacademic support immediately upon arriving at NCU. Based on information gained about Nathan through early contact with Nathan and Sandy, David felt that Nathan would benefit from participating in the full offerings they had for students with ASD. This included weekly coaching appointments and weekly social support group meetings. Richard was the primary support provider through Disability Services. He had a weekly standing appointment with Nathan to develop a rapport with him and for coaching. This is a proactive step NCU Disability Services takes for students with ASD. David and Richard explained that they schedule weekly appointments for students transitioning from high school to NCU so that the student learns if there is a concern with anything, the student will come to David or Richard. They explained that they may not be able to solve the issue a student is having, but will help them to resolve the issue. David explained that this is done because “the first time away from home is nothing to be taken lightly. The anxiety just skyrockets with this population.” These new experiences may be stressful for all students embarking on the journey from high school to college. However, for students with ASD, they are magnified. The experiences that many students with ASD have of heightened anxiety and difficulty in knowing how to resolve challenges posed by the new environment and experiences of attending an IHE are discussed in the literature by Adreon and Durocher (2007), Auston and Vallajo Pena (2017), and Glennon (2001). However, IHEs taking a proactive stance through scheduling ongoing appointments, or other proactive steps is not

presented in the literature as a means of supporting students with ASD, nor is the use of coaching.

Coaching from freak-out to function, emerged as a theme during data analysis. This theme illustrates that coaching was a highly beneficial aspect of Nathan's nonacademic support. David shared that they use coaching because, "You can't just give advice and tell students what to do, because nobody does it!" Coaching allows the student to come to a conclusion on his or her own, on an action item he or she is going to take. This process helped Nathan get through situations in which he was "freaking-out," and in developing his ability to independently think through challenging situations. Through this process Nathan went from freaking-out, or a state of being paralyzed by overwhelming feelings of not knowing what to do as a freshmen, to being able to recognize he is having a challenge, and either handling it on his own or, if needed, seeking out support from Disability Services, or other sources.

Social support group, a group NCU Disability Services cosponsors with the counseling department, Nathan reported was very beneficial. He termed it as "Autistics Anonymous." This group provided Nathan a place to discuss socialization with other students with ASD, and with guidance from professionals to assist in the understanding of social interactions. David reported that Nathan was very active in the group. It was a place where he could let his guard down and discuss issues related to ASD—a safe place. However, once outside the group his guard was up and he did not interact in the same way with other group members. Nathan expressed that it was helpful to know he was not alone in his social experiences associated with ASD. A topic that was often discussed

that Nathan felt helpful was dating. Over time Nathan's role in the group became one of a mentor to younger students.

Barnhill's (2014) study revealed that IHE professionals working with students with ASD were very committed to the success of these students. The theme, individualized approach by dedicated professionals that emerged in the current study provides the same findings. These findings in this theme demonstrate that it was not merely the types of support that led to Nathan's success, but the who and how they were provided. Nathan not only shared about the intense support they provided him, but also scenarios about support he observed them providing to other students. Nathan relayed that Richard was always available, even on the weekends. In addition to going above and beyond their job duties, Nathan also described David and Richard as having a deep understanding of the needs of students, and that they cared. Sandy stated, "I really do appreciate the NCU disabilities department. It has been outstanding. I think it is a big part of his success and ability to live on campus." Sandy also commented on how helpful it was that Richard was available when Nathan was freaking-out. Nathan discussed that there were times when Richard had come to his dorm room when his mom had contacted him indicating he was freaking-out. Nathan's experiences demonstrated the strong dedication; David and Richard have to student success. David and Richard's support was not bound by office hours, or walls, but aimed to support Nathan and all students in finding resolution to individual challenges in whatever way needed.

Academic accommodations. NCU does not see academic accommodations as the biggest concern for most students with ASD. However, they do recognize their importance and provide them with zeal. David stated the "Academic accommodations

are the easy part.” According to Barnhill (2014) and Brown (2017), IHEs provide accommodations with an academic focus more frequently than accommodations and other supports with a sensory or social/communication focus when supporting students with ASD. Unlike the gray area of the legal mandate to accommodate students relating to social/communicational and behavioral aspects of ASD relating to nonacademic situations, academic accommodations are clearly afforded under ADA and ADAAA. IHEs are mandated to provide “reasonable accommodations” for students who are otherwise qualified in order to provide equal access to education without altering the essential elements of the academic programs (ADA, ADAAA). For Nathan these accommodations consisted of extra time on quizzes and exams (started at time and a half and increased to double time) in a reduced distraction environment, permission to record lectures, be provided guidelines and instruction for complex assignments in advance to allow additional time for completion, provide copies of the professors’ notes or lecture outlines if appropriate and available, and a note taker for certain classes. Of these accommodations, Nathan uses the double time on test and quizzes, in a reduced distraction environment the most. He took most of his tests in a room in the disability services office, which had special lighting.

To receive academic accommodations, his professors are sent a letter informing them of his accommodations at the beginning of each semester, along with information that may assist them in working with students with ASD. With only a couple of exceptions, Nathan expresses that his professors have been great at meeting his needs and following the accommodations. In fact, he stated sometimes when professors got the letter, they would be excited to have a chance to go speak with David. David has worked

with professors to educate them on disabilities and support them as needed. He and Richard have a good rapport with professors, which translated to ease in receiving accommodations for Nathan.

General supports services. Brown (2017) describes general support services as services that “provide transition, educational, and social support beyond the level of reasonable accommodations; however, they are programs offered by institutions to a variety of students (Brown, 2017, p. 145).” These services may at some institutions be provided under ASD Specific Services (Brown, 2017). At NCU Nathan utilized several general support services to meet needs related to his ASD and comorbid conditions. Nathan received support in accessing these services through his coaching. These supports included: meeting with professors during their office hours to gain clarification on any content Nathan was unsure of, going to tutoring provided by the Engineering department so that he would be able to get through math homework quicker, rather than remaining stuck, and individual counseling sessions. In addition, Nathan’s advisor was aware of his needs and was able to assist him in selecting course loads each semester.

Question 2. In what ways is a student with Autism Spectrum Disorder supported by his family, while attending a four-year Institution of Higher Education?

Family support for Nathan came from his mom, Sandy. The role Sandy played, while specific to Nathan’s needs, mirrored that presented in the limited literature relating to family support for students with ASD attending IHEs (Barnhill, 2014; Crawford, 2010; Mitchell & Beresford, 2014; Schlabach, 2008; Shmulsky, Gobbo & Donahue, 2015).

Support from Sandy emerged as the theme; Support from Mom— invisible, but essential. Sandy played an essential role in Nathan’s ability to integrate into, and be

successful at NCU. However, this support needed to be invisible, as Nathan was concerned about social stigma. He explained,

Because in America having your mom help you is a weakness. Because of gender stereotype roles. Because if you were a female, it wouldn't be a problem—ah her mom is here and she is spending time with her. Because I am a man, a male, they see that as oh, he is a mama's boy. Oh he is not a man, not independent. So if they see my mom on campus they will think oh, wow. What a dork.

While he does not like to have his mom seen on campus, Nathan does appreciate and at times relies on her support. Consistent with Barnhill's (2014) study Sandy's support was valued, by the student, Nathan, and the institution, NCU.

Sandy has a deep understanding of Nathan's needs, and how he integrates with his environment. Having this deep understanding was critical as she supported Nathan in selecting and integrating into NCU. As deemed valuable by VanBergeijk, Klin and Volkmar (2008), Sandy provided support in identifying the IHE that best suited Nathan. They assert that parents should assist the student in determining "the goodness of fit" in terms of the size of the university, typical class size and how amenable the IHE is in working with the students with varying disabilities, including ASD. Sandy coordinated the visits to the IHEs and with the application process for NCU Disability Services. The role of coordinator is one that is typical for parents of students with ASD to take (Barnhill, 2014; Mitchell & Beresford, 2014; Schlabach, 2008; Shmulsky, Gobbo & Donahue, 2015; Szentmiklosi, 2009).

David and Richard discussed that particularly during the transition to NCU and the early phases of Nathan's integration into college, the role Sandy played was essential.

Sandy worked with David to establish the needed physical accommodations of a single room and educated them about Nathan's needs. She functioned as a liaison between Nathan, and disability services until Nathan was able to directly communicate with David and Richard. That is Nathan would not, could not communicate directly. So mom passed on information about concerns. David stated that Nathan did not like this, and that was because of his ASD that she had to do so. However it needed to occur for him to succeed.

Early on Sandy also played an essential role in developing physical accommodations that resulted in Nathan being able to stay in the dorms. Having a deep understanding of his needs allowed her to predict areas that would be a challenge. The shared showers were one such issue, and perhaps the biggest, due to Nathans fear of germs. Sandy, once able to see the dorm environment, came up with and made a system that would prevent anything from touching the surfaces, to accommodate his fear of germs. Nathan did state that after living in the dorms for 2 years, significantly lessened this fear.

Sandy continued to support Nathan throughout his stay at NCU, even when he was able to independently seek out support from David and Richard. Her ongoing support included emotional support. Both Nathan and Sandy discussed that Nathan calls her to discuss a variety issues at all hours of the day and night. Nathan stated,

Maybe I won't be able to see Richard the same day, or maybe it's the middle of the night, and I am freaking out with no one to talk to. So, I talk to my mom and it actually makes me feel a lot better.

Another area of support that Sandy and Nathan discussed was ongoing help with medical issues. These issues have been acute, such as when Nathan cut his hand and did not know how to get help or when he had let an illness go too long without medical care. She also continues to support Nathan by going with him to medical appointments, due to Nathan's difficulty in communicating with the doctor, and his uneasiness in going on his own.

Running small errands and chores, activities of daily living is an area that Sandy at times provides support. Nathan may call Sandy to have her pick something up for him if he is overwhelmed, or if she is at Nathan's apartment and notices something needs to be done, such as a load of laundry (takes with her), or garbage needs to be taken out.

Despite Nathan wanting the support provided by Sandy to be invisible, he has a good relationship with her. He is appreciative of her support and stated;

She has always been there defending me, helping me out, and being able to try to learn and get help for my problem. She has probably been the most understanding person for my problem. I don't think anyone understands my problem more than she does.

Sub-question 3; how does a student with Autism Spectrum Disorder experience support while attending a four-year Institution of Higher Education?

The details of the support Nathan received are presented above in sub-questions 1 and 2. Thus, there is no need to repeat that information. What this question examines is Nathan's experience, or response to the support. Nathan's experience of support is where the intersection of Nathan's intrinsic features intersects with the extrinsic factors at NCU. There are multiple aspects to his experience. At the heart is the support he receives;

intertwined in are intrinsic factors he brings. Among the most significant intrinsic factors that influence his experience of support are disclosure, extreme perseverance toward his goals, and his impairment of ASD and its effects.

When reflecting on his experience of support, Nathan provided the following depiction of his support as a tower.

My mom is the slab or the land. I wouldn't have been able to build anything without her...David and Richard, I see them as structure, the support beams. They are the foundation, helping me build the tower. They are solid. Because without them, I don't think I would have been able to get this far. David and Richard helped me to get to the point where I don't need their help as much anymore. I am able to build some levels myself. My advisor, she is like the tools to build the structure; how I want to build my tower, the schematic. She helps me get the blueprints out nicely—where do I want my life to go.

This depiction of his support as a tower matches the views he has expressed throughout the interviews. That is, he sees his mom as a constant, always being there. As noted above she understands his impairment better than anyone. Nathan expressed she has always advocated for him. Sandy is there to talk to at any hour of the day when he has a problem and talking to her always makes him feel better. That is his mom is an extremely stable force in his life. However, as with the land or the slab of a building, it is unseen once the structure is built. Sandy's support needed to be unseen when Nathan was at NCU as discussed above. He viewed her support on day-to-day activities both helpful and unwanted. That is, he wanted to be independent, but at times when he was overwhelmed with class work, her assistance was very helpful.

In regard to David and Richard, Nathan sees them as the “structure—the support beams. They are the foundation, helping me build the tower.” Nathan says that David and Richard are his primary support while attending NCU. He recognizes that they not only provide support, but also have enabled him to take on the building on his own. An example of this is when Nathan was describing Richard’s process of supporting students, or coaching. “He likes to like guide the student to like look at their resources have them kind of like figure out what do you think you should do, like ok why don’t you do this— suggestions and stuff. It’s really nice this whole process is really nice.” Nathan feels he has learned the process and is able to problem solve by implementing the process himself. Nathan also feels that they have the authority to support him in terms of making sure he is accommodated and supported within NCU. Nathan sees the fundamental reason that David and Richard provide a high level of support is “because they care and you can tell they actually care. They are not doing this for a paycheck and they go beyond their duty. They go beyond what is required of them every single day.”

Nathan’s expressed that his advisor, the tools to build the structure, has played a big part in his success. Nathan stated that she knows him, and what type of course load he can take. He stated, “My advisor, she really helps me out. She helps me choose my classes and she teaches me stuff as well. I have learned so much just working with her and doing research and stuff.”

While Nathan views the individuals who support him in and the support he receives as positive, he is challenged by his need for support. He stated,

I don't really like getting support, but I know without it, I can't do it. I tried....

Without the support system, I can't. I don't think I can function as well as I want to. Like I might become a B student. That sucks for me! That's like an F!"

It is his drive toward "being the best" that allows him to accept the support and accommodations provided by Disability Services. However, the acceptance of support comes with stress of peers finding out.

One of the themes that emerged in this study is ubiquity of disclosure. This theme presents Nathan's strong conviction towards not disclosing to peers, yet it is always present. Among the reasons for this decision are current cultural responses to autism an invisible mental impairment, past experiences of discrimination and his desire to be treated the same as anyone else. Nathan goes to great lengths to appear "normal". Nathan defines normal as, "Looking like someone who doesn't have a disability. Looking like someone who doesn't have a weakness in a certain area. Being able to make that weakness into something that looks like strength," Nathan stated,

I don't share with my peers that I have a disability, because I don't want people to see me as this thing, rather than who I am. I don't want to feel like less of a person because of it.... I don't want people to pity me at all. I want them to just look at me as any person.... I try very hard to act normal.

Nathan has gone to great length to develop typical mannerisms. So, that he can look "normal." Keeping his disability from peers is constant. David stated, "He is carrying some anxiety constantly." Nathan is not alone in his desire to not disclose. Often students will not even disclose to receive accommodations (Barnhill, 2014; Smith 2007; Wolf, Thierfeld Brown & Bork, 2009).

Only one study was found in the literature that addressed the student experience of support. Schlabach (2008) conducted a multi-case study of five students with ASD that were attending three different institutions. Only one of the students lived on campus. This study identified that support was derived from the same sources that Nathan received—Disability Services, Family and Advisors. As with Nathan, four of the five student's families assisted with the selection of a college. Unlike Nathan the majority of these students seemed to rely mostly on their families for support. This included areas such as learning to manage schedules, and advocacy. The roles that Disability Services and Advisors played varied from student to student. However they did not match the type of support received by Nathan. Students in this study, as with Nathan, attributed the academic success to features of their ASD.

Conclusion.

The findings in this study provide a deep rich understanding of the support Nathan, a student with ASD, received while he attended NCU. He received comprehensive individualized support through Disability Services that addressed his predicament of attending NCU and having ASD, and support from his mom, Sandy. Both the support from NCU and from Sandy played critical roles in his success, and at times were intertwined.

NCU Disability Services or David and Richard, take a holistic approach to supporting students with ASD. While needed academic accommodations are provided; the focus is on nonacademic support. The need for nonacademic support, for students with ASD, is consistently presented in the literature regarding ASD and higher education

as a priority (Adreon & Durocher, 2007; Dillon, 2007; Schlaback, 2008; VanBergeijk, Klin, & Volkmar, 2008; Wolf, Thierfeld-Brown & Bork, 2009). NCU provides a more proactive approach than the literature presents. This study found that proactive early nonacademic support provided by NCU was the cornerstone of Nathan's success, and included involvement of Sandy until rapport was established with Nathan.

NCU starts the proactive approach by reaching out to students and their families prior to the student starting at NCU. David was in contact with Nathan and his mom, Sandy, the summer prior to Nathan's start at NCU. A majority of contact was with Sandy. Early contact with students and the families is a practice taken by IHEs in supporting students with ASD, and is recommended (Barnhill, 2014; Crawford, 2010; Dallas, Ramisch & McGowan, 2015; Schlabach, 2008; Shmulsky, Gobbo & Donahue; Wolf, Thierfeld Brown & Bork, 2009). This early contact led to David and Richard being aware of Nathan's needs and planning accordingly.

A second aspect of the proactive nonacademic support is the services they offer specifically for students with ASD. These services began upon Nathan's arrival at NCU and include social skills support group and standing weekly coaching appointments. While no detail is presented, support groups are listed as a support some IHEs provide (Barnhill, 2014). However, there is nothing in the literature regarding use of coaching. The proactive approach taken by NCU was a highly successful approach for Nathan, and based on data collected by NCU, for other students as well. The data indicated that students who fully participate, were invested in the process of coaching and social group, achieved higher grades and the retention rate was 100%. For students who did not participate, the retention rate was 75%.

Coaching was of great value to Nathan. It is a method of guiding students rather than telling them what to do. It allows the student to come to a conclusion on his or her own rather than being told what to do. The theme coaching from freak-out to function presents the value that this method had in assisting Nathan through times of extreme challenge. It helped Nathan get through situations in which he was freaking-out and in developing his ability to independently think through challenging situations. Through this process Nathan went from freaking-out, or a state of being paralyzed by overwhelming feelings of not knowing what to do as a freshmen, to being able to recognize he is having a challenge, and either handling it on his own or if needed seeking out support from Disability Services or other sources. It is common for students with ASD when embarking on the new experiences of college to become overwhelmed (Adreon & Durocher, 2007; Auston & Vallajo Pena 2017; Glennon, 2001).

The specific approach that David and Richard take as professionals also contributed to Nathan's positive outcome. This emerged as the theme individual approach by dedicated professionals. To assist students they use a highly individualized approach. Their focus is not merely concerned with meeting the legal mandate to accommodate, but are concerned with the wellbeing of the whole student, and focus on each student's individual needs. This is in alignment with Smith's (2007) assertion that "It is not the disability that must be accommodated but rather the individual needs of each student" (p. 516).

Support from Nathan's mom was essential. Sandy has a deep understanding of Nathan's needs, and how he integrates with his environment. Having this deep understanding was critical as she supported Nathan in selecting and integrating into

NCU. Once, Nathan was able to rely on David and Richard, Nathan still sought emotional support and help with other non-college related needs.

This case demonstrated that there is a need for a significant amount of support for students with ASD as they transition from, home and high school, to living away from home, attending college and becoming a productive part of society. The NCU approach is an innovative and effective approach to meeting the needs and is in alignment with the Interactive Model of Disability. When this lens is used to draw conclusions to the findings, it can be seen that the extrinsic factors at NCU—comprehensive support and supportive faculty—work toward minimizing disabling effects of Nathan’s impairment.

Recommendations for Practice.

The limitations of a single case study were presented in Chapter 3. With that in mind, this researcher sees value in using results of this study to inform practice.

Recommendations for IHEs. This study shows that a holistic approach to support for a student attending a four-year IHE resulted in academic success, as well as tolerance to a new living environment, and increased independence from family and greater reliance on the NCU. Data from NCU indicated that gpa was higher among the students that fully participated in the services they offered, and there was a 100% retention rate for those students. These positive outcomes which are quite different from those in the “National Autism Indicators Report: Transition to Adulthood,” (Roux et al, 2015). Thus, it is recommended that the proactive approach outlined in this study provided by NCU be implemented at other IHEs.

Recommendations for high school personnel. The following recommendations relate to planning for student transition to an IHE. First, the professionals assisting students in the transition process should be educated as to what types of challenges lie ahead for students at an IHE; having this knowledge will allow for effective transition planning. This is being recommended because David and Richard discussed that there is often little or no preparation for students with ASD to transition to an IHE. Also, it has been my experience, having worked in adult services including working with students transitioning from high school, that despite it being the responsibility of SPED teachers to develop transition plans, they did not have a clear understanding of what lay on the other side of the transition. Thus, the transition could only provide a cursory preparation.

Transition to college planning should be afforded to all students with ASD whether the student has the formal requirement of transition plan due to receiving SPED, or not. Exactly who would be assigned this role would depend on the school district. The transition planning should look at all the supports the student has in his or her current environment, and research how the support can be transferred to the new environment at the IHE. Some support such as a clinical counselor or psychiatrist may need to overlap with the new practitioner until rapport is established.

A final recommendation relating to transitioning to an IHE would be to develop a support group for high school students relating to transitioning to college. Including college students who have ASD as mentors to the group would be beneficial. Hearing from slightly older peers who have or are experiencing college would be beneficial. During the meetings different colleges could be reviewed regarding the support they provide. Also, scenarios of different challenges that could arise may be discussed. Every

aspect of college should be discussed so that students are aware of the vast differences between high school and college. The significance of any piece of information should not be underestimated.

Recommendations for Future Research

It has been more than 20 years since the diagnostic criteria for Autism broadened to include more individuals with average and above average intellectual ability (APA, 1994); and 10 years since Smith's (2007) exploratory study. Smith's study investigated the needs of students with ASD and what services and accommodations were available for them at IHEs. She found the lack of appropriate accommodation for college students with ASD. The accommodations did not take into account the unique needs of the students with ASD. Smith included recommendations for further research to identify possible accommodations that are beneficial to students with ASD.

Pleas for research have echoed throughout the past decade. Yet, as evidenced by the systematic literature review conducted by Gelbar, Smith and Reichow (2014), there still remains a dearth of research to inform practice in supporting students with ASD at IHEs. Practices are informed by antidotal information passed on from one dedicated professional experiencing success in meeting the needs of students with ASD to another. One such cornerstone in the field, and source for much of what informed this researcher's literature review on the needs of students with ASD is Wolf, Thierfeld Brown and Bork, (2009) *Guide for Professionals*. As evidenced by the findings in this exploratory case study, there are practices in place at NCU that afforded Nathan success as he attended a four-year IHE. There is an urgent need to expand upon this research and gain empirical

evidence on a broader scale. More comprehensive research of successful existing support programs, their practices and their outcomes needs to be conducted at individual IHEs and those findings need to be compared to practices across IHEs in order to gain information that can inform practice of providing support at IHEs and to work backward to inform the transition from secondary education. This is an urgent matter, as there are approximately 50,000 individuals exiting secondary education. The picture painted in the 2015 *National Autism Indicators Report: Transition into Young Adulthood* is very bleak. While the results of this study showed a very favorable outcome for Nathan, the literature indicated that he is an exception rather than the rule, as are the services provided at NCU.

Specific inquiry in follow-up to this study. Conduct a longitudinal study involving a cohort of NCU students that go through the proactive approach. The study should begin collecting data in the students' freshman year and continue for at least 1 year post graduation. Data should be collected regarding demographic information, type of high school transition planning and support provided, specific intervention provided by the NCU and frequency, challenges the students' experience, parent involvement and academic and social success at NCU. Once students have graduated, collect data for 5 years on post graduation outcomes.

Studies should be conducted to determine if coaching produces increased independent problem-solving skills in college and high school students with ASD.

Other considerations in conducting research. In addition to the above specific areas of inquiry, research should be conducted in the following areas.

This and the prior unpublished study I conducted concluded that parent support is an essential aspect of success for students with ASD as they prepare to attend and attend

college. This is also supported in the literature. However, success cannot be limited to those students who have parents who are able to perform this role. Having spent the last 7 years in Title I schools, where many parents are unable to—for a wide range of reasons—support student academic needs. Thus, we must identify the roles parents play in successful college students and offer alternatives to parental support. This would reduce disablement and provide greater opportunity for more capable individuals to attend college and become active and contributing members of the communities in which they live.

Another area that should be explored is the use of the Interactional Model of Disability as a way of teaching about the predicament of ASD and other impairments. The model would need to be further defined. A 3-D Interactional Model would be recommended to provide a visual representation of the process of the interaction between, impairment, individual factors, and external factors. Upon development of such a model, research into the impact of its use in teaching and knowing about disability should then be conducted.

Summary.

This chapter presented discussion of study findings. The discussion included the use of the Interactional Model of Disability as the theoretical lens that guided the interpretation of the data in this study. It included an oversimplified way of viewing the Interactive Model of Disability as three components: impairment and its effects, intrinsic factors of the impaired individual, and extrinsic factors which interact to construct the experience of disability. This was followed by responses to the questions that guided this

study. The overarching question: In what ways is a student with Autism Spectrum Disorder supported while he attends a four-year institution of higher Education?

In order to gain a comprehensive perspective of the support the student with Autism Spectrum Disorder received while attending a four-year institution of higher education, the following sub- questions were explored.

1. In what ways is a student with Autism Spectrum Disorder supported, by the four-year institution of higher education he is attending?
2. In what ways is a student with Autism Spectrum Disorder supported by his family, while attending a four-year institution of higher education?
3. How does a student with Autism Spectrum Disorder experience support while attending a four-year institution of higher education.

The study conclusions were presented. Among them, this case demonstrated that there is a need for a significant amount of support for students with ASD as they transition from home and high school, to living away from home, attending college and becoming a productive part of society. The chapter concluded with recommendations for practice that emerged from the findings and recommendations for future research.

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APPENDIX A. STUDENT INVITATION LETTER

Dear _____ University Student,

My name is Laurie Crawford, a doctorate student at the University of the Pacific in the Benerd School of Education. This correspondence is to invite you to participate in a study I am conducting, “Students with Autism Spectrum Disorder While Attending a Four-Year institution of Higher Education”. You were selected as a possible participant in this study because you are a student at a four-year institution of higher learning and have a diagnosis of Autism Spectrum Disorder (ASD).

The intent of the study is to improve and expand opportunities for individuals at four-year institutions of higher learning whom have ASD. This study will achieve this through gaining in-depth information about the ways in which students with ASD are supported as they attend a four-year institution of higher education.

If you choose to participate in the study, it will involve sharing information about your college experience as a student with ASD and the support you receive associated with your diagnosis of ASD. The information will be gathered through interviews with you, the disability service provider at your institution and a family member. It will also include gathering any documents relative to the support you receive while attending _____. This will allow a complete view of all aspects of the support you receive while attending _____.

If you are interested in finding out more about participation in my study please contact me via email or phone (see below) to set up a time that I can meet with you. At the meeting I will explain the study and your, *the potential participant*, role in greater detail and answer any questions you may have that would help you to decide if you are interested in volunteering to participate in this study.

In closing I appreciate your consideration of this offer to participate in my study “Support Experienced by Students with Autism Spectrum Disorder While Attending a Four-Year institution of Higher Education;”. I look forward to hearing from you.

Sincerely,

Laurie J. Crawford
(209) ---- ----

APPENDIX B. PARTICIPANT CONSENT FORMS

Student Informed Consent Form for Participation in the Research Study Entitled Students with Autism Spectrum Disorder Support While Attending a Four-Year institution of Higher Learning; Collective Case Study

Researcher: Laurie J. Crawford
Doctoral student in Benerd School
of Education at the
University of the Pacific
(209) --- -----

Dissertation Chair Dr. Thomas Nelson
Curriculum and Instruction Benerd School
of Education at the
University of the Pacific
(209) --- -----

You are invited to participate in a research study. The purpose of the study is to gain in-depth information about the ways in which students with Autism Spectrum Disorder (ASD) are supported as they attend a four-year institution of higher education. You were selected as a possible participant in this study because you are a student at a four-year institution of higher education and have a diagnosis of ASD.

The study will involve in-depth interviews with you, the disability service provider at your institution and a family member. It will also include gathering any documents relative to the support you receive while attending the North Coast University (NCU). This will allow a complete view of all aspects of the support you receive while attending The NCU. Information will include your background relative to your attending NCU, issues related to support received while attending NCU and your view of your experience.

I would like to introduce myself, Laurie Crawford-researcher. I am conducting this study in partial completion of my Doctorate degree in Education at the University of the Pacific Benerd School of Education. Provided below is more specific information so that you may make an informed decision regarding choosing to participate.

Thank you, for considering this opportunity.

Benefit of Participation: Your participation will assist in the understanding of the lived experience and support needs of students attending a four-year institution of higher education who have ASD. The information gained in this study is intended to be a step toward provision of support needed in order for increased number of students diagnosed with ASD to attend and graduate from four-year colleges. Currently there is an under

representation of students with ASD attending and graduating from four-year institutions of higher learning.

Risks of Participation: Risks to you are minimal. Minimal risk is described as no greater than other risks you experience everyday. You should be aware that participating in this in-depth interview process, about and relating to your support experiences could bring up areas that might, depending on the individual, cause emotional discomfort. The researcher will work to minimize such occasions. Also, while every effort will be made to protect your identity (see section on confidentiality) there are times when unforeseen circumstances may occur which makes it not possible to give a 100% guarantee of anonymity.

If you have any questions about the research at any time, please call me at 209- --- ---- or Dr. Thomas Nelson at (209) --- ----. If you have any questions about your rights as a participant in a research project please call the Research & Graduate Studies Office, University of the Pacific (209) 946-7716. In the event of a research-related injury, please advise us, and then contact your regular medical provider and bill through your normal insurance carrier.

Confidentiality: The identity of all individuals participating in this study will be kept confidential. The following steps will be taken by the researcher to keep identities confidential. In written documents relating to the study, pseudonyms will be used rather than the participants and four-year institutions actual names. Original records will be kept in a secure place to guard against the names of participants being accidentally revealed. When transcription takes place pseudonyms or codes will be used in place of participants and institutions.

Use of data: The data collected in this study will be presented in dissertation document and presentation. It is intended to provide a rich description of each students experience including using direct quotes. Findings may also be presented in other professional publications or presentations relating to improving the opportunities of student with ASD to attend and graduate from four-year institutions of higher learning.

Voluntary Participation: Your participation is completely voluntary. Refusal to participate or withdrawal of your consent or discontinued participation in the study will not result in any penalty. The researcher may, at her discretion, choose to remove you from the study for any of a number of reasons.

If you are selected and agree to participate you will:

- Participate in three interviews with Ms. Crawford. Each interview is intended to last approximately 90 minutes.
Initial _____ Date _____
- Provide the name of the Disabled Service Provider that you work with at NCU and consent to let Ms. Crawford discuss the services/support that is provided and

related topics, and review and copy pertinent documents in your file kept at the Disability Services office. Included in the documentation needed is verification of ASD diagnosis enabling you to receive 504 accommodations.

Initial _____ Date _____

- Provide the name and contact information of your family member who provides greatest amount of support while you attend college and by providing this information, consent to have the interviewer, Ms. Crawford contact this family member to discuss the support you require as you attend college.

Initial _____ Date _____

- Allow the interviews to be audio recorded for the purpose of accuracy in documenting the information you provide during the interviews. The audio recordings will be played back and transcribed by Ms. Crawford (you will have the opportunity to review transcripts). The digital recordings will be stored on a computer requiring a password to gain access and on a digital device that is in a locked file cabinet.

Initial _____ Date _____

My signature below indicates I am voluntarily participating this research study entitled Support Experienced by Students with Autism Spectrum Disorder While Attending a Four-Year institution of Higher Learning; Collective Case Study I have read the above and had the opportunity to ask for clarification or additional information I needed to make this informed consent.

Participant's signature

Date

Participant's name (print)

Researchers Signature

Date

Parent Informed Consent Form for Participation in the Research Study Entitled
Students with Autism Spectrum Disorder Support While Attending a Four-Year
institution of Higher Learning; Collective Case Study

Researcher: Laurie J. Crawford
Doctoral student in Benerd School
of Education at the
University of the Pacific
(209)--- ----

Dissertation Chair Dr. Thomas Nelson
Curriculum and Instruction Benerd School
of Education at the
University of the Pacific
(209) --- ----

You are being asked to participate in a research study. The purpose of the study is to gain in-depth information about the ways in which students with Autism Spectrum Disorder (ASD) are supported as they attend a four-year institution of higher Education. Your son, Nathan, has agreed to participate and as part of the comprehensive data being collected about the experience of support, your perspective and experience is needed.

The study will involve in-depth interviews with your son, the disability service provider at the North Coast University (NCU) and yourself. It will also include gathering any documents relative to the support your son receives while attending NCU. This will allow a complete view of all aspects of the support your child receives while attending NCU. You will be asked to talk about background information relative to supporting Nathan, issues you are aware of related to support received while attending NCU and your role in supporting him.

I would like to introduce myself, Laurie Crawford-researcher. I am conducting this study in partial completion of my Doctorate degree in Education at the University of the Pacific Benerd School of Education. Provided below is more specific information so that you may make an informed decision regarding choosing to participate.

Thank you, for considering this opportunity.

Benefit of Participation: Your participation will assist in the understanding of the lived experience and support needs of students attending a four-year institution of higher education who have ASD. The information gained in this study is intended to be a step toward provision of support needed in order for increased number of students diagnosed with ASD to attend and graduate from four-year colleges. Currently there is an under representation of students with ASD attending and graduating from four-year institutions of higher education.

Risks of Participation: Risks to you are minimal. Minimal risk is described as no greater than other risks you experience everyday. You should be aware that participating in this in-depth interview process, about and relating to your child's support experiences could

bring up areas that might, depending on the individual, cause emotional discomfort. The researcher will work to minimize such occasions. Also, while every effort will be made to protect your identity (see section on confidentiality) however, there are times when unforeseen circumstances may occur which makes it not possible to give a 100% guarantee of atomicity.

If you have any questions about the research at any time, please call me at 209- --- ---- or Dr. Thomas Nelson at (209) ---- ----. If you have any questions about your rights as a participant in a research project please call the Research & Graduate Studies Office, University of the Pacific (209) 946-7716. In the event of a research-related injury, please advise us, and then contact your regular medical provider and bill through your normal insurance carrier.

Confidentiality: The identity of all individuals participating in this study will be kept confidential. The following steps will be taken by the researcher to keep identities confidential. In written documents relating to the study, pseudonyms will be used rather than the participants and four-year institutions actual names. Original records will be kept in a secure place to guard against the names of participants being accidentally revealed. When transcription takes place pseudonyms or codes will be used in place of participants and institutions.

Use of data: The data collected in this study will be presented in dissertation document and presentation. It is intended to provide a rich description of each students experience including using direct quotes. Findings may also be presented in other professional publications or presentations relating to improving the opportunities of students with ASD to attend and graduate from four-year institutions of higher Education.

Voluntary Participation: Your participation is completely voluntary. Refusal to participate or withdrawal of your consent in the study will not result in any penalty.

If you agree to participate you will: Participate in two interviews with Ms. Crawford. Each interview is intended to last approximately 90 minutes. Interviews may be in person or through real-time communication method (e.g., phone, Skype, face time...)

Initial _____ Date _____

- Allow the interviews to be audio recorded for the purpose of accuracy in documenting the information you provide during the interviews. The audio recordings will be played back and transcribed by Ms. Crawford (you will have the opportunity to review transcripts). The digital recordings will be stored on a computer requiring a password to gain access and on a digital device that is in a locked file cabinet.

- Initial _____ Date _____

My signature below indicates I am voluntarily participating this research study entitled Support Experienced by Students with Autism Spectrum Disorder While Attending a

Four-Year institution of Higher Learning; Collective Case Study I have read the above and had the opportunity to ask for clarification or additional information I needed to make this informed consent.

Participant's signature

Date _____

Participant's name (print)

Researchers Signature

Date

Service for Students with Disabilities Provider
 Informed Consent Form for Participation in the Research Study Entitled
 Students with Autism Spectrum Disorder Support While Attending a Four-Year
 institution of Higher Learning; Collective Case Study

Researcher: Laurie J. Crawford
 Doctoral student in Benerd School
 of Education at the
 University of the Pacific
 (209)--- ----

Dissertation Chair Dr. Thomas Nelson
 Curriculum and Instruction Benerd School
 of Education at the
 University of the Pacific
 (209) --- ----

You are being asked to participate in a research study. The purpose of the study is to gain in-depth information about the ways in which students with Autism Spectrum Disorder (ASD) are supported as they attend a four-year institution of higher education. (Student) has agreed to participate and as part of the comprehensive data being collected about the experience of support, your perspective and experience is needed. Nathan has signed a consent form giving myself, researcher permission to interview you.

The study will involve in-depth interviews with the student, yourself- Service for Students with Disabilities provider at North Cost University (NCU) and the student's family member who supports the student. It will also include gathering any documents relative to the support the student receives while attending NCU. This will allow a complete view of all aspects of the support (student) receives while attending NCU. You will be asked to talk about background information relative to supporting the student as they attend NCU, issues you are aware of related to support received while attending NCU and your role and experience in supporting Nathan.

I would like to introduce myself, Laurie Crawford-researcher. I am conducting this study in partial completion of my Doctorate degree in Education at the University of the Pacific Benerd School of Education. Provided below is more specific information so that you may make an informed decision regarding choosing to participate.

Thank you, for considering this opportunity.

Benefit of Participation: Your participation will assist in the understanding of the lived experience and support needs of students attending a four-year institution of higher education who have ASD. The information gained in this study is intended to be a step toward provision of support needed in order for increased number of students diagnosed with ASD to attend and graduate from four-year colleges. Currently there is an under representation of students with ASD attending and graduating from four-year institutions of higher education.

Risks of Participation: Risks to you are minimal. Minimal risk is described as no greater than other risks you experience everyday. You should know that every effort will be made to protect your identity (see section on confidentiality) however, there are times when unforeseen circumstances may occur which makes it not possible to give a 100% guarantee of atomicity. If you have any questions about the research at any time, please call me at (209) --- ---- or Dr. Thomas Nelson at (209) --- ---- -. If you have any questions about your rights as a participant in a research project please call the Research & Graduate Studies Office, University of the Pacific (209) 946-7716. In the event of a research-related injury, please advise us, and then contact your regular medical provider and bill through your normal insurance carrier.

Confidentiality: The identity of all individuals participating in this study will be kept confidential. The following steps will be taken by the researcher to keep identities confidential. In written documents relating to the study, pseudonyms will be used rather than the participants and four-year institutions actual names. Original records will be kept in a secure place to guard against the names of participants being accidentally revealed. When transcription takes place pseudonyms or codes will be used in place of participants and institutions.

Use of data: The data collected in this study will be presented in dissertation document and presentation. It is intended to provide a rich description of each students experience including using direct quotes. Comparison among cases will also be presented. Findings may also be presented in other professional publications or presentations relating to improving the opportunities of student with ASD to attend and graduate from four-year institutions of higher education.

Voluntary Participation: Your participation is completely voluntary. Refusal to participate or withdrawal of your consent in the study will not result in any penalty.

If you agree to participate you will:

- Participate in two interviews with Ms. Crawford. Each interview is intended to last approximately 60 minutes. Interviews may be in person or through real-time communication method (e.g., phone, Skype, face time...)

Initial _____ Date _____

- Allow the interviews to be audio recorded for the purpose of accuracy in documenting the information you provide during the interviews. The audio recordings will be played back and transcribed by Ms. Crawford (you will have the opportunity to review transcripts). The digital recordings will be stored on a computer requiring a password to gain access and on a digital device that is in a locked file cabinet. Upon completion of the research the recording will be destroyed.

Initial _____ Date _____

My signature below indicates I am voluntarily participating this research study entitled Support Experienced by Students with Autism Spectrum Disorder While Attending a

Four-Year institution of Higher Learning; Collective Case Study I have read the above and had the opportunity to ask for clarification or additional information I needed to make this informed consent.

Participant's signature

Date

Participant's name (print)

Researchers Signature

Date